University of Alberta

Barriers to Accessing and Accepting Highly Active Antiretroviral Therapy in Western Uganda

By

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ABSTRACT:

This study explored the barriers to accessing and accepting Highly Active Antiretroviral Therapy (HAART) by HIV positive mothers in Kabarole District's PMTCT-Plus programme. Economic barriers, particularly transport costs to the clinic, represented the greatest barrier to treatment. In addition to financial constraints, non-disclosure of HIV status to client's sexual partners, long waiting times at the clinic and suboptimal provider-patient interactions at the hospital also emerged as significant barriers to treatment. Findings from Focus Group Discussions with men in the district suggests there to be a lack of male involvement in HIV/AIDS testing. Increased efforts to involve men in voluntary counseling and testing may facilitate partner disclosure and support and would likely increase HAART uptake by PMTCT-Plus clients. These barriers to treatment need to be addressed to improve HAART uptake, adherence and survival of PMTCT-Plus clients in Kabarole district.

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ABBREVIATIONS AND ACRONYMS:

"3 by 5"	The World Health Organization's Initiative to increase the number of AIDS patients receiving HAART to three-million by 2005.
3TC	Lamivudine
AIDS	Auto Immune Disorder Syndrome
APV	Amprenavir
AZV	Atazanavir
CB-ARV project	Community Based- Antiretroviral Therapy project
DLV	Delavirdine
D4T	Stavudine
d4T	Stavudine
ddl	Didanosine
EFV	Efavirenz
GTZ	The German Agency for Technical Cooperation
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immuno-deficiency Virus
IDV	Idinavir

JCRC	Joint Clinical Research Centre
LCI	Local Council Level I
LPV/r	Lopinavir-ritonavir
MOH	Ministry of Health
NFV	Nelfinavir
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor
NRTI	Nucleoside Reverse Transcriptase Inhibitor
NVP	Nevirapine
PI	Protease Inhibitor
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission (of HIV)
RA	Research Assistant
RTV	Ritonavir
SQV	Saquinavir
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
ZDV	Zidovudine

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CHAPTER 1: INTRODUCTION

HIV/AIDS is considered the most important epidemic affecting the world today. Forty-million people are estimated to be currently living with AIDS, the majority of which reside in Sub-Saharan Africa (UNAIDS & WHO AIDS, 2004). The Republic of Uganda experiences some of the highest rates of HIV/AIDS infection on the African continent, with 114,000 of its population living with AIDS, according to a 2004 estimate (WHO, June 2005). Uganda therefore has a high demand for AIDS treatment. There is currently no cure for AIDS, however, the life prolonging treatment known as Highly Active Antiretroviral Therapy (HAART) is available to those infected with HIV.

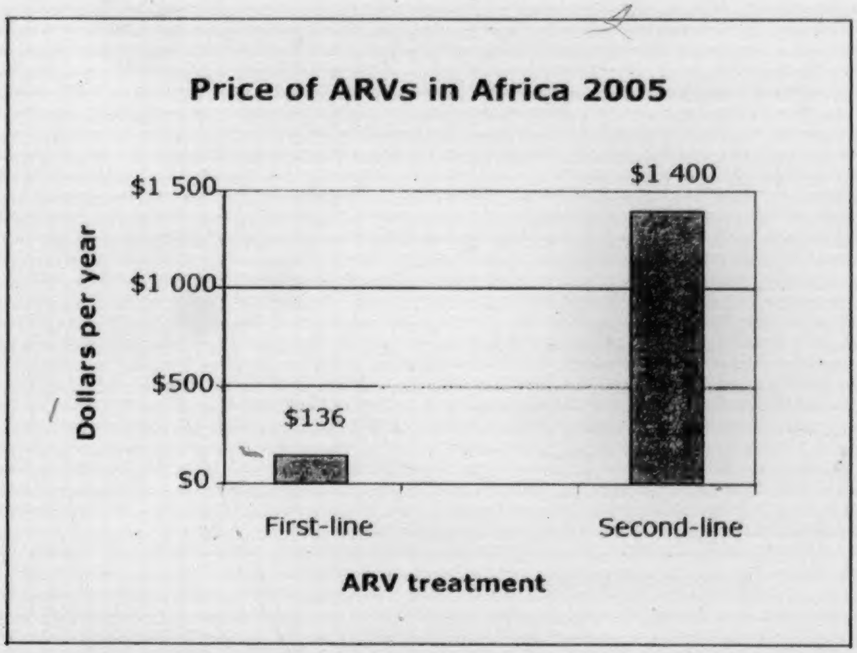
1.1. Overview of HAART

The introduction of HAART has transformed the face of AIDS. HAART has been shown to effectively reduce HIV/AIDS morbidity and mortality in developing countries, prolonging life expectancies, increasing quality of life and adult productivity, thus making AIDS a manageable chronic disease (Ministry of Health, 2003). HAART functions to treat AIDS patients, reduce co-morbidities and may prevent new HIV infections. In Sub-Saharan Africa, HAART is generally comprised of a combination of three antiretroviral (ARV) drugs.

ARV drugs serve to reduce the prevalence of the HI virus in the body. There are a variety of ARVs that act in different ways. The three most commonly used types are: nucleotide reverse transcriptase inhibitors (NRTI's) such as Zidovudine (ZDV,AZT), Stavudine (d4T), Lamivudine, non-nucleoside reverse transcriptase inhibitors (NNRTI's) such as Nevirapine (NVP), Efavirenz (EFZ), Delavirdine (DLV) and Protease inhibitors (PI's) . Saquinavir (SQV), Ritonavir (RTV), Idinavir (IDV), Nelfinavir (NFV), Amprenavir (APV), Atazanavir (AZV) and Tripanavir are examples of Protein inhibitor antiretroviral drugs (Ministry of Health, 2003). Entry inhibitors are a new class of antiretroviral drugs which inhibit the HI virus from entering the T-cells, which play a vital role in the body's immune response. (WHO, 2005 & Ministry of Health, 2003)

Uganda's recommended first line HAART regimen is Triomune, which consists of Stavudine(d4T) and Lamivudine (3TC) plus Nevirapine (NVP) . An alternative first line regimen consists of Stavudine (d4T) and 3TC plus EFZ. Alterations of the HAART combinations are made for pregnant women or those experiencing co-morbidities such as tuberculosis. Patient biological incompatibility, sub-optimal adherence and viral resistance to HAART can lead to treatment failure. In the case of treatment failure, second line regimens are used. The second line regimen recommended in Uganda for treatment failures of the above combinations are d4T/Didanosine (ddI) + Lopinavir-ritonavir (LPV/r) or ZDV/ddI + LPV/r respectively (Ministry of Health, 2003). Second line treatments in sub-Saharan Africa are currently much more costly than first line treatments and therefore, it is preferable to keep patients on first line regimens if possible.

Figure 1.1 : Current Prices ($US) of First and Second line ARVs in Africa



Source: Medicines Sans Frontiers with data from the Clinton Foundation HIV/AIDS Initiative and WHO Global Price Reporting Mechanism

HAART is a life long treatment, characterized by a dosage schedule of two tablets per day, administered twelve hours apart. The requirement of lifelong dosing of HAART is one of the major challenges in taking and adhering to this treatment (Walter Kipp, personal communication). Nearly perfect adherence to HAART is required by AIDS patients taking the treatment in order for it to be effective. Poor adherence can lead to drug failure or the development of drug resistance. These features of HAART may represent drawbacks to starting and continuing treatment. Another drawback is potential drug toxicity. Finally, three major adverse side effects can occur when on HAART therapy: severe allergic reactions, jaundice visible in the eye and peripheral neuropathy, originating in the feet.

The benefits of HAART greatly outweigh the potential drawbacks mentioned above, making HAART a vital tool in AIDS treatment and control. There is a need to treat all AIDS patients with HAART. The "roll out" of HAART treatment in Uganda to increase its access by AIDS patients is being undertaken as part of WHO's "Treat 3 by 5 initiative". ~~Of~~ Uganda's 114,000 AIDS patients over 65,000 are currently receiving HAART, according to a 2005 estimate (WHO and UNAIDS, 2006). The number of AIDS patients in Uganda receiving HAART is substantially higher than in other Sub-Saharan African countries, making Uganda one of the leaders in HAART roll out on the continent. High HAART treatment rates among Ugandans should not foster complacency, as there are still scores of AIDS patients in the country who should be receiving this treatment.

A feature of Uganda's HAART roll out initiative includes the free provision of testing and HAART through the public health care system, which has been available since 2004. HAART is provided free of charge to HIV positive mothers and their families identified through the Prevention of Mother to Child Transmission Plus (PMTCT-Plus) programmes established in antenatal clinics.

1.2. Overview of the Prevention of Mother to Child-Plus Programme

Prevention of Mother to child transmission "Plus" (PMTCT-Plus) programmes, recently conceived in 2001, have been launched in selected antenatal clinics to reduce mother to child transmission (MTCT) and promote maternal survival through treatment with HAART(Ministry of Health, 2003).

Antenatal services are widely available in Kabarole District, staffed by clinical officers and nurses and are attended to by 90% of pregnant women in the area (Dr. Kipp, personal communication). At these antenatal sites, pregnant women are encouraged to visit on average ten times over the course of one's pregnancy. Although ten visits is recommended, many mothers attend once or twice, the average being 2-3 visits. During these visits, mothers are weighed, examined, have blood tested to detect diseases such as syphilis and are counseled and offered testing for HIV.

The PMTCT-Plus programme consists of a preliminary voluntary counseling and testing (VCT) service provided to pregnant women, wherein HIV positive mothers are identified and offered single dose NVP prophylaxis to PMTCT. This regimen consists of one dose of NVP that is administered to the mother at the onset of labour, and a second dose that is given to the baby within 72 hours of delivery. Subsequent to HIV testing, a final post- test counseling session is held, in which mothers are provided with HIV/AIDS information, including preventative measures, coping strategies, nutritional advice, use of MTCT prophylaxis, offered psychosocial support and the option of free HAART and treatment of opportunistic infections(WHO, 2005).

1. 2.1 Eligibility for HAART

HAART eligibility for HIV positive mothers follows the Ugandan National Antiretroviral Treatment and Care Guidelines for Adults and Children (Ministry of Health, 2003). Mothers and their families identified through the PMTCT-Plus programme are given priority access to free HAART. Eligibility criteria include: WHO stage IV irrespective of lymphocyte count (CD4 count), advanced stage IIIB disease exhibiting invasive bacterial infections and persistent or recurrent oral thrush irrespective of CD4 count and patients in WHO stage I, II or IIIA with CD4 cell counts $\leq 200/mm^3$. Following CD4 testing, those women who are considered eligible for treatment are provided with an information pamphlet regarding HAART and invited to return in two weeks to enroll in the free HAART program. During the enrollment process, co-morbidities, psychosocial barriers, motivation and potential for adherence are assessed prior to starting the patient on HAART (Ministry of Health, 2003).

In order to be registered in the PMTCT-Plus programme, women must undergo several steps. Pregnant women must first make the decision to access antenatal clinics. Those who are able to attend the antenatal clinics are generally those who place importance in these services, have the will, mobility, resources and freedom to do so. At the antenatal clinic, these pregnant women are first counseled about HIV/AIDS, testing and HAART and are offered to be tested for HIV. Those women who accept testing and return for their results are offered NVP to prevent HIV transmission to her unborn child. At this point, the woman is registered as a PMTCT client. Women are urged to return to the clinic post delivery for a CD4 test. Those women who return for this test and are deemed eligible to receive treatment (as in section 1.2.1 above) are registered in the PMTCT-Plus programme.

All women enrolled in Kabarole's PMTCT-Plus programme must follow the procedures described above to access postpartum HAART. HAART has been shown to be highly effective in reducing morbidity and mortality if administered properly, and therefore its use in mothers will likely be highly beneficial (Hogg et al, 1998 & Egger et al, 2002). Maternal survival increases the probability of the child's survival (Taha et al, 1996), and ensures the existence of a family for him or her to grow up in. The overall effectiveness of PMTCT programmes is therefore contingent upon promoting maternal survival through ensuring the acceptance of ongoing treatment after delivery.

A PMTCT-Plus programme in Western Uganda was recently launched in 2003 under the support of the German Agency for Technical Cooperation (GTZ). It has since been handed over to the Ugandan Ministry of Health (MOH) and Joint Clinical Research Centre (JCRC) who now claim full responsibility over the programme. Buhinga, a government-run hospital in Kabarole district serves as the referral hospital for the entire region, catering to the majority of women in the area. Among the eligible mothers enrolled in GTZ's PMTCT-Plus programme from 2003-2005, 89 out of the 352 women that were eligible for treatment failed to enroll in the free HAART programme and eight only returned once. Among those who began HAART, a total of 39 defaulted treatment.

This study addressed the cohort of mothers described above, exploring their reasons for failure to access, accept or continue free HAART treatment for their infection. The current paucity of information regarding reasons for poor postpartum acceptance and adherence to HAART makes this research valuable. Follow-up of AIDS patients who have been offered HAART and did not accept or continue free HAART is not routinely done by the AIDS clinics due to an extreme manpower shortage.

1.3 Literature Review

A literature review was performed using the following databases: MEDLINE, NEOS Library Consortium Catalogue and Google. Combinations of the following keywords were used: antiretroviral, HAART, treatment, uptake, acceptance, start, begin, mothers, women, PMTCT, PMTCT-Plus, vertical transmission, mother to child, pediatric, Kabarole, Uganda, Africa, HIV and AIDS. 17 relevant articles were found, six of which were Africa-specific. An additional 12 publications were obtained through cross referencing. Other sources of information utilized apart from the literature search included the Uganda Bureau of Statistics (UBOS), Ministry of Health (MOH), Kabarole District (unpublished data) multilateral organizations (UNAIDS and the WHO) and developmental organizations (GTZ).

Poor uptake of PMTCT services is a common occurrence throughout Southern Africa (Ekouevi et al, 2004; Manzi et al 2005; Turner et al, 2000). Existing studies addressing the factors contributing to poor uptake of PMTCT services primarily focuses on uptake of basic PMTCT interventions, such as voluntary counseling and testing (VCT), PMTCT prophylaxis and alternative/safe feeding strategies, rather than postpartum HAART.

The PMTCT-Plus initiative first conceived in 2001, combines the basic PMTCT services with the additional option of free HAART provision to infected mothers, her partner and children. Because the PMTCT-Plus initiative is fairly novel, data on postpartum treatment, including reasons for low acceptance of HAART by these mothers are lacking (Taha et al, 1996). Existing studies pertaining to reasons for poor acceptance of HAART and basic PMTCT services are likely to be similar to the reasons for poor postpartum uptake of HAART by mothers enrolled in the PMTCT-Plus programme.

1.3.1 Factors contributing to poor uptake of HAART and Basic PMTCT services

Patient readiness has been indicated to directly influence one's choice to initiate HAART. Readiness to start HAART consists of a variety of components including: disease state, knowledge of the disease and HAART, belief in treatment efficacy, social support, motivation, and quality of relationships with health care providers (Fehr et al, 2005; Gebrekristos et al, 2005). These components of patient readiness have also been frequently associated with poor uptake of treatment for PMTCT services.

The role of stigma as a deterrent to participation in PMTCT services in Sub-Saharan Africa is recurrent throughout the literature. Fear of disclosing a positive HIV result to partners, family members and the community are the most commonly cited reasons for nonparticipation (de Paoli & Klepp, 2004; Magnhild E et al, 2006; Painter et al, 2004). Low sero-status disclosure among sexual partners by women is common and attributable to fear of physical and emotional violence, blame, disruption of relationships, abandonment and economic loss (Gaillard et al, 2002; Maman et al, 2001; Medley et al, 2004). Sero-status disclosure among partners is imperative to the success of PMTCT-Plus and HIV/AIDS prevention and control efforts because it increases opportunities for risk reduction and creates a social support network necessary for effective prevention and treatment interventions (Medley et al, 2004).

The patient's experience with the health care institution affects programme participation. The convenience of services such as accessibility, distance, perceived quality of services and infrastructure will determine the likelihood for a return visit (Magnhild et al, 2006; Painter et al, 2004). The relationship with the health care providers and staff courtesy is also extremely influential in a woman's decision to uptake PMTCT services (Gebrekristos et al, 2005). Unpleasant experiences with staff or services will discourage further interactions with the system. Health care providers may be the only reliable resource of HIV/AIDS knowledge available to a patient, making provider-patient relationship and quality of service extremely important.

Insufficient knowledge and understanding of HIV/AIDS risk factors, prevention and treatment is associated with poor uptake of PMTCT services (Gebrekristos et al, 2005; Maman et al, 2001; Painter et al, 2004). In terms of uptake of HAART, it is important that the patient has a functional understanding of the risks of the disease, the procedures, benefits and potential side-effects of treatment. This information should be clearly expressed to the patient by health care professionals.

Financial constraints have also been found to pay a pivotal role in one's ability to access HAART. MShana et al.'s (2006) qualitative study in rural Tanzania on HAART users identified transport costs and supplementary food costs, among others, as substantial obstacles to accessing treatment.

Previous studies have shown that women are less likely than men to access HAART (Kilian, 2002). Cultural, economic and gender imbalances may result in a woman's lack of autonomy over health decisions, limiting access to HAART. Competing demands of childcare may also restrict a mother's autonomy, resulting in a mother neglecting her own health and failing to seek treatment (Turner et al, 2000). Personal factors such as depression in patients may result in a delay or failure to start HAART treatment. Patients who experience a lack of symptoms and feel healthy, despite having a low CD4 count may be likely to defer treatment initiation (Turner et al, 2000).

1.3.2 Factors contributing to Sub-optimal Adherence to HAART

There is some overlap between the factors that prevent patients from starting HAART and the factors that deter them from adhering and/or continuing with this treatment. The principle barriers to HAART adherence in Botswana identified by Weiser et al. (2003) include: financial constraints (such as costs of the drugs), stigma, travel/migration and side effects. Compliance is considered a significant barrier to HAART roll out efforts in sub-Saharan Africa (Harries et al, 2001; Popp et al, 2002). Existing studies regarding adherence in Africa limit their scope to reporting adherence rates and at times population-level risk factors for non-adherence. The desperately needed qualitative research into the behavioral reasons for patient non-adherence is lacking (Gill et al, 2005).

A considerable amount of research has addressed the lack of uptake of PMTCT interventions, however very little data is available regarding treatment of these women postpartum, including reasons for poor access, acceptance and adherence to HAART (Fehr et al, 2005; Gill et al, 2005). Very few publications on the topic of the reasons for poor postpartum HAART acceptance were found using the combinations of the selected keywords referred to above. This illustrates the paucity of information on the topic. The role of HIV/AIDS stigma, fear of serostatus disclosure, confidentiality, HAART knowledge, PMTCT programmes and programme staff in a woman's decision to accept and continue HAART have not been determined. In addition, a male perspective on this problem of low HAART acceptance is unknown. This is valuable information, considering the pivotal role (described above) that male partners play in a woman's decision to partake in and continue HAART. This information will be used to provide recommendations so that changes in PMTCT-Plus programmes can be made, making postpartum HAART more accessible to mothers, thereby increasing HAART uptake and maternal survival.

1.3.3 Background

1.3.3.1 Uganda

Uganda has been hailed an international AIDS "success story" in light of the declining national HIV sero-prevalence announced in 1995. The decline in HIV prevalence can be attributed to Yoweri Museveni's strong political commitment to tackling the disease, following his rise to power in 1986. First recognized in Uganda in 1982, the HIV/AIDS epidemic spread rapidly throughout the country, reaching its peak in 1990-1992. During this period, Uganda was thought to possess the highest HIV prevalence rates on the continent, afflicting 30% of pregnant women in the major urban centers (Kilian, 2002). In response to this overwhelming disease burden, a rigorous HIV/AIDS campaign was launched. Under the support of both governmental and non-governmental organizations, programmes were developed that focused on institutional capacity building, public education for behavioral change, sexually transmitted diseases (STD) management, safe blood transfusion services as well as care and support for people with HIV/AIDS(Kilian, 2002).

1.3.3.2 Kabarole district

Kabarole District in Western Uganda, has benefited from programmes such as those described above. Kabarole is subdivided into three smaller districts: new Kabarole, Kyenjojo and Kamwenge. Together, these three districts have a combined population of just under a million, an estimated 20,000 of which are pregnant women (Kilian, 2002). Kabarole, Kyenjojo and Kamwenge falls under the project area of "Basic health services, Western Uganda", which provides PMTCT services in antenatal clinics (Kilian, 2002). First Supported by the GTZ, PMTCT-Plus programmes have been established in five hospitals and antenatal clinics throughout the district. These clinics are attended by 13,000 women, of which an estimated 8% are HIV infected (Kilian, 2002).

Although Kabarole District's PMTCT-Plus programme was initially run by GTZ, the programme was gradually handed over to the Ugandan Ministry of Health (MOH) and the Joint Centre for Clinical Research (JCRC). By 2005, the complete transition of the PMTCT-Plus programme from GTZ to the MOH and JCRC, who are now fully responsible for the programme, was achieved.

Most PMTCT-Plus clients in Kabarole District rely on public transport to access health care services. There are various different modes of transportation in Kabarole District. In remote rural areas with limited accessibility by roads, choices for transportation are limited. Residents in these areas usually must walk to more populated areas with better roads to catch public transportation. Boda-bodas, motorcycles that can be hired to carry a passenger or two, are the most abundant mode of transportation and can usually be found in more rural areas. On more well used routes, such as major roads, highways or market centres, group taxis and special hire (private taxis) are available. The cheapest mode of transportation are group taxis, followed by the boda-boda and special hire taxi. Transportation cost from rural areas can be quite expensive ranging from 5,000 to 10,000 Ugandan Shillings (approximately $3.00- $6.50 CDN) for a return visit. This represents a significant portion of a household's income, as the national monthly household expenditure in Uganda, according to a 2000 estimate was 9,711 USh (Uganda Country Report)

1.4. Study Design

1.4.1 Purpose of the Study

The purpose of this study was to describe barriers to accessing and accepting life-saving HAART by HIV positive mothers enrolled in Kabarole's PMTCT-Plus programmes. The objective is to provide a comprehensive understanding of mothers' reasons for not accepting or continuing HAART so that recommendations can be made to improve postpartum treatment uptake in Kabarole's PMTCT-Plus programme.

1.4.2 Research Questions

The following questions will be addressed by this study:

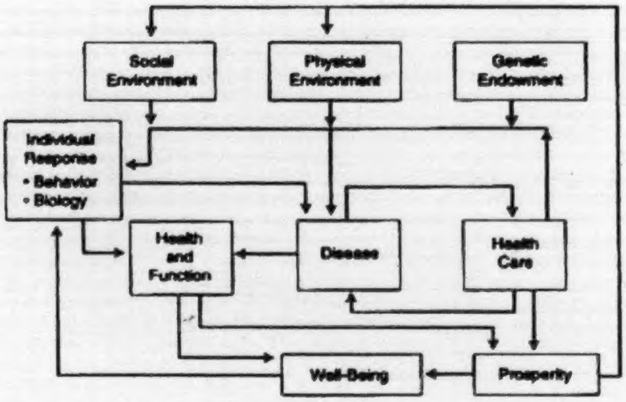
1. What are the barriers to accessing, accepting and continuing postpartum HAART among mothers enrolled in Kabarole's PMTCT programme?
2. What is the level of HAART knowledge among these mothers?
3. What are these women's experiences with the existing PMTCT- Plus programme?
4. What are men's views about the low uptake of free postpartum HAART by mothers?

1.4.3 Conceptual Framework:

Health does not exist in a vacuum, but is influenced by a variety of factors. Evan and Stoddart's "Health Field Model" (1990), is a framework that takes into account the multiple determinants that affect health at the community level. These include: the Social and Physical Environment, Genetic Endowment, Health Care, Prosperity, Disease and Individual Response (Figure 1.1). Unlike the Biomedical model, which describes health simply as the absence of disease, the Health Field Model includes a more comprehensive model of health, incorporating the concept of Well Being and Function.

From this model, it can be assumed that health and health behaviors are subject an array of internal and external forces. This model encompasses the broader environmental components such as the physical environment, social environment, individual and health care factors that affect patients in their decision to access treatment. It is therefore important to consider these factors and their roles in shaping health behaviors such as starting, adhering to and continuing HAART.

FIGURE 2 : A model of the determinants of health. ***Evans RG, Stoddart GL. Producing health, consuming health care.*** **Soc Sci Med.** ***1990;31:1347–1363.***


Social Environment
Physical Environment
Genetic Endowment
Individual Response
• Behavior
• Biology
Health and Function
Disease
Health Care
Well-Being
Prosperity

The Health Field model was used to guide this study and aid in the understanding of aspects that influence women's decisions to take HAART. The various constituents included in the Health Field model, such as environmental, social, physical, health care and individual factors were taken into consideration when conducting the literature review and brainstorming the topic list for interview participants. This allowed a comprehensive literature review and topic list to be achieved.

1.5 Methods

1.5.1 The Research Team and Training

The research team included individuals from Canada and Uganda, possessing a range of different backgrounds. Each member was able to provide invaluable insights, suggestions and skills that enhanced this study.

Members of the Canadian supervisory committee included Dr. Walter Kipp; International Health and Cam Wild; Health Promotion and socio-behavioral health science. They provided constant support and critical insight into the design, implementation, analysis and presentation of this study.

Community Based ARV (CB- ARV) project staff were imperative to the success of this study as the resources and support staff were for the most part supplied by this organization. Having supervised numerous student research endeavors in the past enabled the CB-ARV staff to assist in selecting the most appropriate research assistants for the study. CB-ARV's project manager, Tom Rubaale, acted as the field supervisor, overseeing the study. Study activities were also approved and supervised by Kabarole District's Officer of Health.

Selection of research assistants (RAs) were made under the recommendations of the CB-ARV manager. Criteria for selection included: previous research experience, knowledge of the topic, person-ability and an excellent command of both English and Rutoroo. Two RAs were hired for data collection and an additional five were selected to carry out transcription and translation of documents.

Training of interview RAs commenced shortly after hiring. The Canadian investigator (Katherine Duff) provided the RAs with the proposal and Topic List drafts as well as additional information about HIV/AIDS, PMTCT-Plus and HAART. These were read in together in their entirety. Discussion and questions surrounding the study objectives followed to ensure that a thorough understanding of the project was achieved. The draft topic lists were read as a group, the purpose and rationale behind each question was discussed. This detailed topic list examination with Ugandan natives was helpful in developing the most linguistically and culturally appropriate topic list for the study. Proposed modifications and suggestions were approved by the Field Supervisor before alterations were finalized.

RAs were trained in data collection and qualitative interviewing techniques. These included: gaining entry, establishing rapport, the process of obtaining informed consent, protecting participant confidentiality, interview methods such as administering semi-structured topic lists, probing and responding to questions. RAs were also trained in the use of recording and transcribing equipment and software. Mock interviews were held, with the primary investigator acting as the interviewee. This exercise was repeated until the Canadian investigator was satisfied with the interviewers' technique. Pre-testing of the topic list was employed on several CB-ARV employees and Fort Portal locals. Adjustments were made based on feedback received, to assure that the topic list was as straightforward, applicable, lucid and as culturally appropriate as it could be.

The five RAs responsible for transcription and translation of documents were also provided with study information and familiarized with the study and topic list. The Canadian investigator trained transcribers in the use of transcription software and desired format of transcripts. The primary investigator supervised multiple transcriptions to ensure interviews were transcribed verbatim and in the correct format. All five RAs were responsible for transcription, and only two were involved in the translation of topic lists and interviews. Two of the transcribers possessed previous experience transcribing and translating interviews. These two most experienced RAs were employed for translation of documents. This number of translators was kept to a minimum to ensure accuracy of translation and to reduce variability between transcripts.

1.5.2 Data Collection:

1.5.2.1 PMTCT-Plus Clientele Participant Recruitment

Participants for the interviews and FGDs with mothers were identified using Buhinga's GTZ PMTCT-Plus records. Clients on the GTZ PMTCT-Plus list were separated into four categories: those taking HAART, those who never enrolled, those who enrolled and never returned and defaulters. These four groups were separated into Urban and Rural residents. Participants were randomly selected within each group. This was done by assigning each participant a number, generating a list of random numbers using excel, and choosing the participant corresponding to each random number on the list, starting at the beginning. If a participant could not be found, the participant whose number corresponded to the next random number on the list was selected. A former employee of the PMTCT-Plus programme located and recruited participants in their homes using the addresses indicated on the register. Employing a former PMTCT-Plus worker served to protect the client's confidentiality. The Canadian investigator did not assist in recruitment, to avoid attracting attention towards the potential interviewee. Recruitment was performed in the most discreet manner, usually during the morning when the woman's partner was less likely to be around. This was done to avoid drawing attention towards the potential participant, in case she had not yet disclosed her status to her partner, friends or family. Once located, participants were taken aside, informed of the study and invited to participate. Upon acceptance, a date, time and place for the interview was organized. Interviewees were informed that they would be reimbursed for transport costs related to participation in the study. It is important to note that there was a high acceptance rate to take part in the study. Only two out of the 52 women who were invited to the interviewed declined the offer. Most of the interviews were conducted in a private room at Buhinga hospital, however, if requested, interviews were administered in the participants' homes.

Recruitment proved to be one of the greatest challenges in carrying out this study. The addresses were often outdated, incorrect or incomplete. Participants residing in urban areas were the most difficult to locate, as most rent and are only transient residents. Those participants residing in rural areas seemed to relocate less frequently and were therefore easier to trace. The initial design specified that participants be stratified by residence in urban and rural locations. This was challenging, as the majority of women dropping out of the program resided in rural areas and those residing in urban areas were often impossible to locate. For these reasons, obtaining comparable numbers of urban and rural participants was problematic. Although participants' residences were documented throughout the study, the selection and separation of participants according to residence was abandoned.

Participants who were feeling physically unwell were not excluded for the study, as this would have represented a bias in participant selection. Of the women who were selected and contacted for recruitment, only one was found to feel too unwell to be interviewed (suffering from malaria) at the time of initial contact. This participant was interviewed two weeks later, after she had recovered from her illness.

1.5.2.2 Exclusion Criteria

Participants aged 18 or younger were excluded from the study. Participants who were involved in in-depth interviews were also excluded from Focus Group Discussions (FGDs) that were carried out later on in the study. The aim of this exclusion criterion was to obtain a range of perspectives on the issue of poor postpartum HAART access and acceptance.

1.5.2.3 In-Depth Interviews

The nature of a research question indicates the most appropriate methods to answer the query at hand. Since the research questions attempt to address the question "why" rather than "how much" or "how many", it seemed most appropriate that qualitative methods be employed.

In-depth interviews with clients were the first to be conducted. In-depth interviews were deemed the most appropriate method in this context, especially considering the sensitive nature of the topic. Respondents may be more comfortable sharing information regarding their status and personal life to one interviewer as opposed to a group. The one-on-one nature of in-depth-interviews also allows for probing so that a deeper understanding of each informant's situation can be attained. This is less likely to be achieved when FGDs are utilized.

In depth Interviews- Interview Questions

Interview questions administered to all participants stemmed from findings in the literature pertaining to factors contributing to poor uptake of basic PMTCT services and HAART in Africa. These include: HAART knowledge, experience with the PMTCT-Plus programme and programme staff, health care decision-making, disease state, and the effects of HIV/AIDS stigma; i.e. fear of loss of confidentiality and serostatus disclosure/spousal communication. Additional questions were added to topic lists administered to the defaulters and mothers taking HAART. These included: experiences taking HAART, for example, whether or not they experienced side effects, how long they've been taking/defaulting HAART, how many times they had defaulted HAART and reasons for defaulting.

The format for interviews were semi-structured, with the majority of the questions being open ended. Open questions are ideal for this type of study, as it allows the participant to provide an elaborate, detailed response (Morse and Field, 1995). Any closed ended questions were followed by probing questions so that a more detailed response could be provided. Probing questions were also asked if clarification or further information on a particular response was desired. No specific approach to questioning was taken, such as the pyramid or funnel approach, however the questions were organized in a manner the Canadian investigator thought to be logical.

The participants were recruited and interviewed until saturation was achieved. Saturation is the point whereby no new information, ideas or concepts emerge from the data (Morse and Field, 1995). The final numbers of interviews conducted were: 17 with Mothers that never enrolled; two with mothers that enrolled and never returned for HAART; 15 with mothers that defaulted treatment and 12 with mothers taking treatment. The number of participants within the list that could be located also limited the number of participants interviewed. For instance, within the group of mothers that enrolled and never returned for HAART only two of the eight participants could be located, due to outdated addresses or relocation of participants.

1.5.2.4 Female Focus Group Discussions

One FGD with PMTCT-Plus clients was held subsequent to the completion of in-depth interviews. These included women who had defaulted, and those who had never enrolled. These respondents were selected from the PMTCT-Plus register and recruited in the same manner as in-depth interview participants were. Women who participated in in-depth interviews were not invited to partake in the FGD. The purpose of recruiting different respondents allowed a greater breadth on the topic of low access and acceptance of HAART to be obtained. Questions asked in the FGD were modified from the original in-depth interview topic list, focusing on topics that previous interview participants had identified as important.

The social dynamic of FGDs allows the participants to interact and is a method to extract attitudes, perceptions, knowledge and experience about the topic being discussed (Kitzinger, 1995). This interaction between participants may also elicit information distinct from that obtained in interview. Kitzinger (1995) and Ulin et al (2002) both expressed that observing the types of social interactions and exchanges that occur during FGDs is important in understanding social and cultural norms, values and beliefs. Considering the context of differing social, cultural and linguistic differences in which the primary investigator is carrying out this study, FGDs seemed to be the most logical method to use. FGDs also served to complement and enhance the information obtained from in-depth interviews.

The female focus group included seven participants, five of whom had defaulted treatment and two that never enrolled. The FGD was held in a private room in the out-patient's department of the hospital. FGDs began with an icebreaker activity in which each person introduced themselves. This exercise was an attempt to make the participants more comfortable with one another so that they could speak without reservation. The FGD lasted for about 2 hours followed by a one hour question period.

1.5.2.5 Male Focus Group Discussions

Four Male FGDs were held, two in urban locations and two in rural locations. Convenient sampling was used to recruit participants. In each case, the Local Council I (LCI) Chairperson was informed of the study, and he/she gathered seven to ten participants to be involved in the study. The LCI typically provided a quiet interview space, usually in their homes, to avoid noise interference and interruptions.

Participants for the Male FGDs were selected by convenient sampling from both urban and rural areas. Inclusion criteria for the FGDs will be males between the ages of 18 to 45. As with the Female interviewees, participants were fully briefed on the study prior to enrollment. FGDs were conducted in a quiet, private location where interviews could be carried out without interruption.

Topics discussed in the male FGD were derived from the in-depth interviews. Male/partner-related reasons for not taking HAART that were identified in the in-depth interviews were incorporated into the topic list so that these issues could be explored from a male point of view. The topic list (Appendix XIV) included knowledge of HIV and HAART, testing, HIV Sero-status disclosure among partners, social support and men's views and speculations on reasons for low uptake of free HAART by mothers.

1.5.2.6 Participant Remuneration

Research participants were not paid for participation in the study. This was done to prevent a level of expectation which may lead to contamination of future studies. Participants were however reimbursed for any transport costs associated with involvement in the study. If interviews were conducted in the informant's homes no remuneration was offered. Small souvenir gifts such as Canadian pens, pads of paper or soap and matches were presented as a token of the appreciation for involvement in the study.

1.5.2.7 Impact of the Study

Study impacts began during the process of data collection. Throughout the initial stages of participant recruitment, PMTCT-Plus client records were updated and corrected as clients lost to follow up were located. Missing, incorrect or outdates information regarding clients addresses, treatment and survival status were corrected.

Following each interview and FGD session, participants were provided with the opportunity to raise any questions or concerns they had regarding treatment with a clinical officer. Most patients were issued an appointment or were visited in person by their physician to discuss the possibility of starting or restarting treatment. A number or respondents were enrolled and restarted on HAART as a result of these meetings. Some PMTCT-Plus clients also took the opportunity of paid return transport to consult health care workers regarding other ailments. A handful of respondents brought their children to be tested for HIV.

Participant's concerns and suggestions regarding the services received at the yellow house were raised at a staff meeting at Buhinga's HIV/AIDS clinic so that services could be improved. In addition to this, several transcript excerpts containing comments relevant to service delivery were provided to the hospital's medical superintendent by CB-ARV project manager. Hopefully this information will be used to improve provider-patient interaction and service delivery.

The Male FGDs also served to increase HIV/AIDS and HAART knowledge among participants involved. All FGD sessions were followed by question periods in which respondents were able to voice any questions or concerns they had about HIV/AIDS or HAART. It seemed that villagers found these sessions both important and informative, as sessions lasted between one and two hours, and many respondent expressed appreciation for being involved in the study. Villagers were encouraged to test for HIV and were provided with contact information of a clinical officer if any additional questions or concerns arose.

A copy of study results and recommendations will be compiled and submitted to Buhinga and Virika hospitals. Hopefully, this information and recommendations may be used to improve service delivery and uptake of HAART by PMTCT-Plus clients in the district.

1.5.2.8 Data Recording

In-depth interviews and FGDs were carried out in Rutoroo by two RAs. If English was preferred, the interview was conducted in English by the Canadian investigator. Most of the interviews and all of the FGDs were attended by the Canadian investigator. Throughout the interviews, the Canadian investigator was responsible for taking field notes, ensuring recording equipment was functioning properly, providing direction to the research assistant and answering any questions posed by the interviewee or research assistant.

One digital and one manual tape recorder were used simultaneously in each interview. This measure was taken so that a copy of the interview would be available if one of the devices were to malfunction. Spare batteries were also kept on hand.

Some technical difficulties were experienced during the data-recording process. The loud noise created by rains falling on tin roofs was almost unavoidable. This proved to cause significant interference in recording, making conversation undecipherable and/or inaudible. In most cases, the recorder was turned off and restarted once the rain had subsided, but due to the unpredictable lengths of rain sessions, sometimes interviews had to be continued despite persisting rainfall. Three interviews were discarded due to rainfall interference resulting in inaudibility of the interviews. Another technical difficulty included the length of the tapes used in the manual tape recorder. Most interviews and all FGDs had a duration longer than the one and a half hours that the manual tape could hold. This led to some gaps in transcripts between pausing and switching tapes. Since the digital recorder recorded simultaneously, the problem of running out of tape was insignificant.

1.5.3 Methodological Rigor

The most commonly used criteria for assessing methodological rigor in qualitative studies as described by Lincoln and Guba (1985) are: 1) truth value or credibility, 2) applicability, 3) consistency and 4) neutrality. Im et al.(2004) suggests that research conducted in cross cultural settings are presented with a slew of concepts and phenomenon such as cultural, language, sociopolitical, religious, practical and historical issues that are unlike those in usual research settings. For this reason, a special set of criteria should be used in assessing methodological rigor in cross cultural settings. Evaluation criteria identified by Im et al.'s (2004) literature review of rigor in cross cultural research include: 1) cultural relevance, referring to whether the research addresses the population's issues and interests (Meleis, 1999); 2) contextuality, whether sufficient understanding of the research context exists; 3) appropriateness, concerning whether or not communication styles, conceptualizations and the translation process are applicable in the research setting (Elder, 2003); 4) mutual respect, recognizing the value of participants views, values, beliefs and eliminating any hierarchies that may exist between researcher and participant (Elder, 2003); and finally 5) flexibility, which refers to whether the researcher was flexible regarding language and time use (Meleis, 1999).

Measures were taken to fulfill each criteria used to assess methodological rigor. Prior to the onset of the study, a literature review was conducted regarding the topic of poor acceptance of free HAART, primarily in sub-Saharan Africa. Committee members and students who had previously lived and conducted research in Kabarole shared their experiences and perceptions of Kabarole with the Canadian investigator. Upon arrival in Uganda, staff of the Institute of Public Health at Makarere University and the Fort Portal-based field supervisor examined the study design, providing suggestions to yield a more appropriate study design. Examples of changes made include; the wording of topic lists, more appropriate and discreet methods of recruitment, and interviewing in participants homes rather than solely in the hospital. Living, working and interacting with the Fort Portal community enhanced the researcher's understanding of the culture and context in which the research was being conducted. Incorporating male perspectives on the topic of poor postpartum acceptance of HAART through FGDs served to provide a holistic view of the topic and enrich the investigator's knowledge of the research context.

Throughout the development and implementation of this study, communication with Dr. Moses, who was the doctor in charge of the former GTZ-Run PMTCT-Plus program. Dr. Ali Moses was familiar with the workings of the program and was well acquainted with the PMTCT-Plus clients chosen to participate in the study. The support of this research by a local doctor assured us that this study topic was relevant to Kabarole's residents and that they would benefit from the findings of this study. Furthermore, copies of the study results were requested by the medical superintendents of both Buhinga and Virika hospitals, so that improvements in service delivery can be made. Study participants benefited directly by participating in the study. Following interview and FGD sessions, respondents were presented with the opportunity to raise any questions or concerns they had surrounding HAART with a clinical officer. Any misconceptions they expressed were clarified during this period. Many of the interview participants were started or restarted on HAART subsequent to the interviews.

The issue of linguistic appropriateness was tackled by employing Fort Portal locals to conduct interviews in Rutoroo and translate them into English. Topic Lists and transcripts were back-translated to ensure accuracy of translation. Interview questions were pre-tested by various locals for comprehension and cultural appropriateness. Throughout the study, the Canadian investigator referred to the field supervisor, CB-ARV staff and RAs to explain and elaborate on the meanings of phrases, behaviours and/or practices observed from a Ugandan perspective. Communication styles between the Canadian investigator and participants improved over time as insight into the intricacies of the Ugandan culture and lifestyle were developed.

The utmost effort was made to ensure that interview participants felt comfortable and were treated with respect. The Canadian investigator was careful not to impose any of her values or beliefs on the interview participants. Respondents were informed that they could speak freely and any insights provided were valuable. The Canadian investigator carefully listened to and considered all the information and suggestions offered by interviewees.

Flexibility regarding time and language were applied to the fullest extent. Interviews were conducted at times and places specified or agreed to by the participant. Missed appointments were rescheduled. The span of the four months allotted for research allowed flexibility within that time to arrange as many interviews as necessary. Interview languages were dictated by the interviewees. Between the Canadian investigator, data collection RAs and translators, English, Rutoroo, Swahili and Baganda were spoken fluently. All four of these languages were utilized over the course of this study, depending on how the interview participant thought she/he could communicate most effectively. Both English and Rutoroo topic lists were brought to interviews. Although most interviews and FGDs were conducted in Rutoroo, there were two participants, one in the female FGD and one in an in-depth interview that were not proficient in either English or Rutoroo. For these two participants, the English versions were translated into Swahili and Baganda so that the respondent could answer the questions. If it was found that the translations did not portray the true meaning of the intended questions, the interview was discarded. One in-depth interview (conducted in Baganda) was discarded for this reason.

1.5.4 Verification

Verification of the data was ongoing throughout the interview process. The Canadian investigator ensured that leading questions, which would force verification, were not asked. Leading questions implies the answer or includes the information the interviewee is looking for. The interview questions were designed to be open ended, so that the interviewee could respond freely without prompting from the interviewer. The respondents' answers were often repeated back by the interviewer to be validated by the respondent. Probing was utilized to elucidate and expand on any unclear responses from participants. This measure guaranteed the participant's responses were not misinterpreted. In addition, an audit trail was constructed over the course of the study, which includes information from field notes and memos regarding changes to the topic list as well as the principle investigator's personal views and perceptions of the ongoing study.

Verification during the transcription and translation process included: The comparison of Rutoroo transcripts to the original audio-recording to ensure transcription accuracy and the comparison of Rutoroo transcripts to English transcripts by a different translator to evaluate accuracy in translation. Any differences were identified and corrected. Ambiguous or culture-specific terms and phrases were double checked with the interviewer, transcriber and translator to make sure that the meaning of the respondent's original statement was maintained.

Verification during the data analysis was conducted. A colleague independently coded interview transcripts. Transcripts were compared for agreement in codes and categories. Codes would be added or removed based on the outcome of this exercise. Theoretical verification was conducted, whereby the related literature was reviewed for similar findings. Such a search demonstrates how the study findings fit into the existing body of knowledge on the topic (Morse & Field, 1995).

1.5.5 Limitations

The participants chosen for this study were drawn from Buhinga's GTZ PMTCT-Plus register. Given that the responses from these individuals are embedded in the context of Kabarole district and in particular, Buhinga's PMTCT-Plus programme, this study's findings may not be applicable to PMTCT-Plus clients elsewhere. This is an anticipated restriction of a qualitative study wherein a specific population and environment is being examined.

The sensitive nature of the topics discussed may give rise to limitations, one of which is "social desirability bias". Social desirability bias is "A bias in self-report instruments created when participants have a tendency to misrepresent their opinions in the direction of answers consistent with prevailing social norms" (Polit & Beck, 2004 p.284). This may have occurred more frequently during FGDs, as there are more people listening to and judging the respondent. FGD dynamics also give rise to the "negative effect", wherein participants may withhold or alter responses that may conflict with the group's general view (Kitzinger, 1995). This negative effect might have been observed during the male FGDs. For example, in the first FGD, when asked if they'd heard about HAART, the majority of the participants indicated that they had, following the first few positive responses by participants. In the second interview however, the first two respondents indicated they'd never heard about HAART. This was followed by several other respondents to express they also had never heard about the drug. This may represent a genuine discrepancy in HAART knowledge between the two FGDs or could be a result of the negative effect, whereby non-conforming responses were silenced.

Several unavoidable limitations arose due to the cross-cultural nature of this study. One of these limitations was the "Mzungu effect". The Canadian investigator attended all interviews and FGDs. The presence of a foreigner may have brought about distrust or discomfort in the informants thus altering or impeding free response. In addition to this limitation, the delicate nature of the discussion topic may have served to restrain honest, uninhibited dialog. Employing in-country researchers as interviewers, conducting icebreaking exercises and carrying out interviews in participant-chosen locations were attempts to make the respondent feel as relaxed as possible. The presence of a foreigner may also have been a limitation in that respondents may have overstated their poverty, hoping for financial assistance from the Canadian investigator.

The RA/interviewee interaction and consequent level of mutual comprehensible communication was potentially compromised in some situations. This is a natural circumstance in any language between two people but, in this case, because the principal investigator did not speak the interviewing language and could potentially miss the level of comfort and flow in discussion, she might have been unaware of an incidence of miscommunication, which was subsequently not shared afterwards by the RA. This potential miscommunication is therefore a potential limitation. However, the principle investigator was always present, was raised in an environment of different cultures and different languages and was therefore sensitized to the body language and intonations in communications between two people which increased her likelihood of picking up on any sign of this potential limitation and dealing with it.

Language posed as a substantial barrier and may represent a limitation to this study. Documents were translated and transcribed multiple times. This could lead to a loss of meaning and/or misinterpretation of the data. Various measures were taken to alleviate this problem such as the pre-testing and altering topic lists, cross-checking transcripts, spot-checking translations and back translation of topic lists and other documents. It cannot be guaranteed, however that all language-barrier limitations were eliminated.

The selection bias typically associated with hospital-based studies applies as a limitation to this study as well. Respondents were recruited off the GTZ PMTCT-Plus client list. This cohort of women represents those within the district who possess the characteristics, motivation and resources to access health care services in the first place. The characteristics of these participants may differ from other women in the district who did not attend the hospital during their pregnancy, accept testing and return for their HIV test results. For this reason, the barriers to accessing and accepting treatment among this group cannot be generalized to the entire female population of Kabarole district.

Male Focus Group Discussion participants were recruited in a different manner than interview participants. This difference in recruitment strategies represents a potential limitation because the perceptions expressed by these men may not necessarily be consistent with the perceptions held by the spouses of the PMTCT-Plus client interviewed. In an effort to mediate this limitation, men were sampled from the areas from which most respondents resided. This recruitment strategy is based on the assumption that those living in the same area have similar access to HIV/AIDS and HAART information and therefore will posses similar perceptions on the topic of low postpartum HAART uptake. Although it would have been ideal to recruit the partners of interview participants, this was avoided to protect female participant's confidentiality and safety.

The final limitation is generalizability. The context of this study are Buhinga hospital-specific and study participants represent a specific cross-section of health care users. The data generated from this study therefore may not be generalizable to other settings.

1.5.6 Ethical Considerations

Biomedical ethics provides principles to evaluate research. Ethics principles typically cover respect for persons, beneficence and justice (MJ Ahn et al, 2003). Various measures were taken to abide by biomedical ethics principles so that ethical soundness could be achieved.

Ethical clearance for this study was first received from the University of Alberta's Health Research Ethics Board (Panel B) at the University of Alberta. Upon arrival in Uganda, final approval was granted by the National Council for Science and Technology in Kampala and the District Director of Health Services (Dr. Okech) in Kabarole District, Uganda.

Ethical merit embraces respect for the integrity, privacy, safety and human rights of research subjects (Benatar, SR, 2001). It is for this reason that special consideration was put towards protecting and embracing these values.

The recruitment of participants by a healthcare worker from Buhinga hospital ensured that the participants' confidentiality was maintained within the health care setting. Interview locations were also chosen with the informant's privacy in mind. The criteria for choosing interview locations were: accessibility, discreetness and privacy. Interview locations chosen were places where interviews could be conducted discreetly, without interruption. Alternative locations were used when specified by the participant. The majority of interviews and female FGDs were carried out in a private room in Buhinga hospital. Other interviews were conducted in particpants' homes, when requested. All of the Male FGDs were carried out in areas agreed to by participants, usually a private room in the LC1's home.

Prior to commencement of in-depth interviews and FGDs, participants were informed of the nature, purpose and objectives of the study so that consent could be sought. Marshall (2001) documented language and cultural barriers as one of the many pitfalls researchers face when obtaining informed consent. In order to address the issue of language and cultural barriers and effectively communicate the details and requirements of the study, a local RA carried out the procedure of informed consent in Rutoroo. The Canadian investigator assured that the informants fully understood that participation was voluntary and that they could withhold response or withdraw from the study at any time. Respondents' signatures indicated an agreement to partake in the study. Informants who were illiterate were asked to provide a thumb-print in the signature space in lieu of a written autograph. Interviews were commenced only after informed consent had been received.

Study participants' privacy was protected by allotting each respondent a number, as the data was collected. The numbers corresponding to the participants were used as a substitute for the individual's name and will be used in all works that ensue. Names will be excluded in all reports, presentations and documents resulting from this study. A record of participants' names and their corresponding numbers has been kept by the principle investigator, however will not be revealed to anyone other than the primary investigator, Dr. Walter Kipp. Access to confidential data will be restricted to the Canadian and principle investigator. This data was locked safely in a filing cabinet in Uganda and will remain there for duration of five years, after which it will be destroyed.

The sensitive nature of the topics discussed demanded that social support could be offered, in the case that the interviewing process may distress the respondent. The principle supervisor and RA were available for immediate support and the contact information of a social worker was kept on hand for referral. Fortunately, there was no need for the use of these measures over the course of this study.

1.6 Data Analysis

Data Analysis followed methods outlined by Rothe (2000). This began with an overall surface reading of the transcribed data. This phase of data analysis was ongoing; overall surface readings were performed within 72 hours of the receipt of the English transcripts. Any recurring concepts or ideas emerging from the data were noted. Once all of the English transcripts had been received, each interview was read line by line and categorized. Categories are labels given to similar ideas or concepts expressed in the data. Once a category code was developed, a definition of the code as well as a description of how to recognize it was documented (Boyatzis, 1998). A master list of all the categories and their respective definitions were then compiled. Following a compilation of a category list, the response frequency of all participants for each category was tallied. This exercise provided the Canadian investigator with an idea of the categories and themes which the informants may find most prominent.

Once a list of categories was compiled, a category framework was assembled, which matched quotations from the data set with their corresponding categories. Initially, there were 23 categories. These 23 categories were then collapsed into 12 categories. Further grouping and reorganization of these categories into overarching themes followed. The 12 categories were grouped based on similarities in concepts into five themes.

CHAPTER TWO: RESULTS

The following section describes the results derived from the in-depth interviews, and focus group discussions as well as findings from the FGDs with men. Data analysis from the female in-depth interviews and FGDs resulted in the creation of 12 categories and five subcategories falling under five major themes. The major themes are: Economics, Health Care Services, HIV/AIDS and HAART knowledge, Social Environment and lastly, Patient physical health and disease state. Instances often arose whereby a concept could easily fit in one category/theme or another. In these cases, concepts were categorized in way that the Canadian investigator thought most suitable. The themes and categories are outlined below:

1) Economics

- *Clinic visit-related costs*
- *Treatment related costs*

2) Health Care Services

Experiences with the Programme Staff

PMTCT-Plus programme services

3) HIV/AIDS and HAART knowledge

Patient HAART Knowledge and Beliefs

Sources of HAART knowledge

Misconceptions

4) Social Environment

HIV/AIDS Stigma

- *Non-disclosure*
- *Fear of Relationship Disruption*
- *Views of PLWHA*

Social Support

Women and Powerlessness

- *Health Care Seeking Decision making*
- *Home and work responsibilities*

5) Patient Physical Health and Disease State

Experience of side effects

Asymptomatic state/ feeling healthy

These and categories describe the contextual realities that influence this study's participants' decisions to start or continue their life-saving HAART treatment. The categories and themes induced from the data support Evan and Stoddart's Model of Health (Evans and Stoddart, 1990) that indicate a variety of contextual factors such as Physical, Social, Health Care and Personal influence health. Explication of this study's results will begin with a brief description of the PMTCT-Plus clients enrolled in this study.

2.1 Description of Study Participants

As previously mentioned, four groups of PMTCT-Plus clients were interviewed: 1) Those that never enrolled for free HAART, 2) enrolled but never began treatment, 3) defaulters as well as 4) patients currently taking HAART. Respondents were asked to provide some of their socio-demographic information such as their age, marital status, occupation, residence, number of children and their husband's status. An general description of participants' socio-demographics is provided below.

Group One: Never enrolled for treatment

A total of 17 clients that were found to be eligible but never enrolled for free HAART were interviewed. Participants' ages ranged from 19-49 years, the average age of interview participants being 30 years of age.

The majority (12/17) of participants were married and currently cohabitating with their partners. One participant was single and the remainder were widowed. Most husbands/partners had been tested for HIV, either together with her partner or secretly. Four of the respondents' husbands refused testing, and two were known to have tested secretly. Of those partners known to be tested, nine were found to be HIV positive and two were reportedly found to be HIV negative. Of the nine HIV+ partners, only one was taking HAART.

All but one of the participants had children, the number of children ranged from one to eight. Roughly half of these children were tested for HIV and one was found to be HIV positive and on HAART.

Peasant farming was cited by all participants as their primary occupation. Respondents' partners were more likely to hold a job outside of farming. Seven of the respondents' partners were described as working as a mechanic, business man, teacher, soldier and herdsmen. The remainder of partners worked at home as peasant farmers.

Women's education level were as follows: four participants having never attended school; two respondents had studied up to secondary one and three (equivalent to grades eight and ten), two respondents held a P7 (grade seven equivalent) education and the remainder held a P6 (grade six equivalent) or less. Women's partners generally tended to possess an equivalent or higher level of education.

Most participants (12/17) hailed from various rural areas on average an estimated 10 kms away from the hospital. Other respondents lived in urban areas, three of whom lived in the Fort Portal municipality, within walking distance of Buhinga hospital.

Group Two : Enrolled and Never Returned

Only two participants (Respondent #21 and #22) interviewed had enrolled and never began treatment. These women were aged 27 and 45 years of age. Their education levels are P5 and P7 respectively and they both work at home as peasant farmers with their spouses. Both respondents were married, however only one partner was known to be tested and found HIV negative. Participants #21 and #22 had seven and six children each, none of which were diagnosed HIV positive.

Group Three: Defaulted HAART

14 clients that had defaulted HAART were interviewed. Some respondents' ages ranged from 27 to 39 years. The ages of defaulters were slightly higher than those that had never enrolled for treatment.

Only six of the 14 defaulters were married. Five of the respondents were single and three were widowers. Only five of the respondents were cohabitating with their partners. Of the six married respondents, five stated that their partners had tested for HIV/AIDS and one claimed her husband had refused testing. The last respondent was unsure whether or not her husband had tested for HIV. Three of the five tested were HIV positive, but were not taking HAART. As in group one, most participants had children. Two respondents had HIV+ children who were both on HAART. The most common occupation cited by respondents was peasant farming. Only two women held non-farming jobs such as owning a retail shop and selling shoes.

The education level among defaulters ranged from none to S4 (grade 11 equivalent). Four of the women had no formal education, six had P3-5 and two had reached S3 and S4 (equivalent of grade 10 and 11). As in group one, the majority of participants lived in rural areas, between 5 to 18 kilometers away. Only one respondent resided in an urban area, 11 kilometers from the hospital.

Respondents were also asked how many times they had defaulted HAART and the length of each defaulting period. Eight respondents had defaulted once and never returned for treatment. The time elapsed since these respondents had last taken HAART ranged from two months to over a year. Two participants explained that they had defaulted several times before restarting treatment. One participant had defaulted over three times and was now on the last line of treatment. Four participants confessed to having defaulted only once before returning on treatment. The length of these treatment abscondments ranged from one month to a year.

Group Four: PMTCT-Plus Clients Taking HAART

Twelve clients currently taking HAART who had never defaulted treatment were interviewed. The ages of these respondents were typically older than clients that had never enrolled or defaulted treatment.

The greater part (10/12) of group four respondents were urbanites, living in relatively close proximity to the hospital. Most urban respondents described the distance between their homes and Buhinga to be between two and six kilometers.

Unlike the participants not taking treatment, most respondents in group four were not married. Of the 12 participants interviewed, five were married, three were widowed, one was separated, one was engaged and two were single. Of the married respondents only two claimed to be currently cohabitating with their partner.

Spousal testing among these participants was high with four of the five clients' spouses having been tested for HIV. The four clients' partners that tested positive were not taking HAART at the time of the interview. Similar to the other groups interviewed, most respondents stated having from one to six children. None of these clients' children that were tested had been diagnosed with HIV.

The education level of group four participants seemed to be similar to the other groups, with one having no education, one with S3 (grade 10 equivalent) and the remainder having attained primary education ranging from P2 to P7 (grade two-seven equivalent). Again, most respondents claimed to be peasant farmers. Four stated having other jobs such as owning a kiosk, working in police administration, making and selling crafts and working as politician.

2.2 Household Economics

Poverty was the prevailing backdrop for the greater part of the PMTCT-Plus clientele that were interviewed during this study. Poverty often dictated patients' ability to access and adhere to HAART. Scarcity of financial resources needed to take HAART were mentioned by the vast majority of women who were interviewed, including those who never enrolled, enrolled and never returned, defaulted as well as women currently taking HAART. Only three of the 46 women interviewed claimed that HAART-related costs were not an impediment to taking treatment.

The majority of the interview participants sustained their livelihoods exclusively or primarily through peasant farming. Many women explained that as peasant farmers they were reliant on their crops for money. Any excess crop not consumed by the household was sold to generate income. Dependence on garden harvests means that cash flow is subject to the seasonality and productivity of the crops being grown. Poor garden productivity often leads to a lack of funds available to put towards treatment-related costs. Many respondents mentioned that their crops were barely enough to sustain their families alone, and very little surplus was generated. The following quotation demonstrates a peasant farmer's reliance on her crop for treatment-related costs:

> *For me I try to dig and plant dodo and other vegetables but this is where I also get food and they are not even enough and if I sell cabbages at 100 Shillings (6 cents CDN) it will not fetch enough to bring me here and go back home. Therefore I saw that I could not manage to keep coming.*
>
> (FFGD R8-Defaulted HAART)

Having cash is often rare for these farmers and difficult to come by, especially for those who do not possess livestock that can be easily liquidated or a formal job paying a salary. This lack of cash represents a major challenge in undertaking clinic visits as expressed below:

> *"What [caused me to default HAART] was poverty in our homes. You don't have a goat, you don't have a cow, you don't have a chicken and you don't have a job, then where does one get money for coming here to collect drugs and then going back home?" (*Defaulted HAART- R6 FFGD)

The above quotations illustrate the economic context in which many of the PMTCT-Plus clientele live, providing insight into some of the financial challenges faced that impact their decisions to start and continue HAART.

Financial constraints manifested every facet of these women's treatment seeking health care decisions as will be expounded below.

2.2.1 Hospital visit related costs: Transport Costs

Although HAART itself is provided free of charge, the hospital excursion required to obtain the drug remains costly. High transport costs were the most commonly cited barrier to taking treatment and was mentioned by all four groups interviewed. Only nine out of the 46 women interviewed claimed that transport costs did not represent a challenge to taking treatment. HAART patients are required to frequent the hospital regularly, especially during the early phases of treatment. When just beginning HAART, patients are obliged to make monthly visits to the hospital to collect their drugs and meet with their physician. Monthly visits are scheduled so that the physician can assess adherence, compatibility and the effectiveness of the HAART in the patient. After this initial period, patients are only required to attend the hospital every second month, and undergo two CD4 tests per year. The high transport costs associated with hospital visits represented a significant burden and barrier to treatment. This is especially true for the majority of clients, who live in distant rural communities, where transport was often unavoidable, unavailable and costly. Most of the PMTCT-Plus clients described transport costs to and from the clinic for check-ups, follow-ups and refills as a major barrier to taking treatment. The following quote illustrates the predicament of excessively high transport costs:

"Sir, [transport] is a hindrance. It is too much for a normal village person. I am jobless so it is difficult for me to get money so I could even spend a whole year without getting treatment". (R17- Never Enrolled)

This statement suggests that the anticipated difficulty in obtaining transport money for clinic visits deters women from returning to enroll in the free HAART program. This sentiment was shared by many of the participants interviewed.

Lack of transport money was commonly cited as a barrier to taking treatment as well as a reason for defaulting treatment:

> *"[The reason I defaulted was] the transport issue. Sometimes the transport money would not be enough and I would miss coming so I would feel like if I miss one month, then I should completely give up on HAART".* (R31- Defaulted HAART)

> *" .... We sold almost all of the property and I continued with my drugs but afterwards I failed to come back because of transportation. We had sold most of the things at home and I saw if I continued selling them, then there would be nothing left for the children in case we died. I had to stop [HAART]."* (Defaulter R48-27)

Many of the women interviewed, especially those not taking treatment resided in rural areas up to 30 kms away. The average distance to Buhinga hospital from participants' homes was approximately 10kms. In an effort to save money, many clients would walk the long distances to the clinic to pick up their drugs or meet appointments. Respondent 32 recounts sometimes walking the ten kilometers from her home to the clinic:

> *"Sometimes I will walk most of the way and sometimes I will get a boda boda all the way. It depends on how weak I am feeling. But to go to and [from] on a boda to my house it costs 6,000 shillings ($3.89 CDN). Sometimes if I have no money I will walk all of the way" (*R32-Defaulted HAART)

Unfortunately, when the clients are feeling physically unwell they are unfit to walk the long distances to the hospital where the drugs are dispensed:

> *" Sometimes if I don't have the money I will walk, but at the times when I am feeling sick and weak, those times I cannot walk to the hospital."* (R51-Taking HAART)

The above citations illustrate the common barrier of high transport costs that hinder patients from accessing HAART. Transport is not the sole cost incurred by clinic visits. Other logistical costs associated with taking HAART medication and other clinic-visit related costs are divulged below.

2.2.2 Hospital visit-related costs: Purchased meals

The MOH/JCRC-run HIV/AIDS clinic at Buhinga hospital experiences a high patient load and severe staffing shortages that result in unavoidable congestion and long wait times lasting up to a day or longer. Due to wait times of four to five hours on average, patients must factor in the cost of purchased meals during this period. The necessity of purchasing meals was expressed primarily among women who had experiences with the new MOH programme; that is clients who were taking and had defaulted treatment.

"The total transport cost is 6,000 ($3.89CDN). If you add the cost of lunch to that, the total is about 10,000 ($6.50). That's why I decided to first rest on the drugs". (R29-DefaultedHAART)

" Sometimes [the problem is] the transport. Secondly, when you come up there and you don't have lunch in your pocket, you are hungry". R36- Taking HAART

The extra cost of purchased meals increases the financial encumbrance associated with clinic visits that act as a barrier to accessing and accepting treatment. The long wait times at the MOH clinic also resulted in other additional costs such as spending the night in Fort Portal as well as the indirect costs of missing work and leaving the children at home.

2.2.3 Spending the night

Several respondents that were taking or had taken HAART mentioned that visits to Buhinga often meant spending the night in Fort Portal, thus adding to the already high clinic-visit costs. The PMTCT-Plus clients explained that long wait times indirectly forced them to stay in Fort Portal for the night. After waiting a day and not receiving the attention or treatment sought, a handful of patients explained that they were forced to spend the night in Fort Portal and return to the hospital the next day:

"... I waited until six in the evening and had to spend a night at a friend's home." (R29-Defaulted HAART)

Overnight stays were a product of the long wait times at the clinic, especially among those who lived in distant villages. Long wait times often caused patients to miss their ride home, as there is a limited availability of transport in the evenings.

"Sometimes we would leave the clinic at six in the evening and for those of us who were coming from far we would go back complaining because transport in the evenings would be very hard. There are even those who would come from Kamwenge and they even had to ask for transfers". (R29- Defaulted HAART)

"... When you are delayed at the clinic you find the cars already left and there you get problems". (R3-Defaulted HAART)

Lack of transport availability at night-time sometimes forced patients to overnight in Fort Portal before returning home.

2.2.4 Missing work – Lost wages

As mentioned above, the majority of women interviewed were peasant farmers, and therefore did not directly associate hospital visits with the financial loss of missing work. There were, however, five out of the 46 interviewed had other jobs. One of these women related long hospital visits with missing time at work:

*Since I am a business lady I always feel like I would miss out on customers because when you come to the clinic you wait so long".(*R31-Defaulted HAART)

Excursions to the hospital can also mean leaving children behind. It was anticipated that the interviewees would express leaving children behind and associated babysitting fees as a cost, however this response did not surface. Most respondents explained that children were left with family members or neighbors, but did not mention any charges associated with this favor.

In Hardon et al.'s 2006 study, user fees and CD4 tests charges were cited as a financial barrier to adhering to treatment. This was not the case in Buhinga hospital where CD4 testing and other user fees are provided free of charge to PMTCT-Plus clients.

2.2.5 Proposed solutions to overcome Hospital visit-related costs:

Hospital-visit related costs, as illustrated by the above citations, were found to be the greatest barriers to accessing and adhering to treatment for all clients interviewed. For many respondents, it represented the primary obstacles to taking HAART. Several PMTCT- Plus clients mentioned various solutions to overcoming the financial barriers to taking HAART. These include: the provision of or assistance with transportation fees, decentralization of services and decreasing the frequency of required hospital visits.

Assistance with Transportation Costs:

Many of the participants inquired about or suggested that transportation remuneration be provided for to patients by governmental or other sources. This question emphasizes the significance of transport costs as a barrier to treatment. Two of the following citations communicate this suggestion:

"*I would like to ask if the government can help people who have no transport by providing transport for them.*" (R34- Defaulted HAART)

"*...and again ask if they [the government] can give us any other kind of help. At least transport apart from free drugs.*" (R50- Taking HAART)

Decentralization of Services:

Another suggested solution to the problem of high transportation costs was made by several women who had defaulted treatment. Both informants proposed that HAART be made more accessible by bringing them to nearby clinics.

> *"At least bring the drugs to the health units in our villages then we don't have to spend a lot of money which we don't even have".* (R48-Defaulted HAART)

> *"For us who have defaulted because of lack of transport, is there any possibility for us to be assisted with transport or if not, can these drugs be brought near our homes for some of us coming from far so that we can resume taking these drugs?"* (R22- Defaulted HAART)

Decrease Frequency of Clinic Visits:

An additional recommendation made by a participant to mitigate the barrier of long distances and high transport costs was to reduce the number of required hospital visits. Decreasing the frequency of visits from monthly to once every two or three months would lessen the overall cost for transportation to the hospital.

> *" It would make it easier [if I could retrieve my drugs every two months] because transport is very high and since I don't have money, it is hard for me to come monthly. If it were a couple of months before I come back, I maybe could manage."* (R31-Defaulted HAART)

> *"[The health care staff] really help me but I wanted the doctor to give me drugs for two months but he said it is not possible."* (R50-Taking HAART)

2.2.6 Treatment-Related Costs : Nutritional Requirements

During the early stages of treatment, HAART patients often experience increased appetite in response to the body's need for extra nutrition as it recovers lost weight and strength. It is therefore important for patients to consume healthful foods such as fruit, leafy green vegetables, meat, eggs, milk and fruit juices during this period. Many of the HAART patients interviewed mentioned that acquiring nutritious foods while on treatment was a challenge. The recommended foods are typically quite expensive and can be unaffordable to most village people.

"Food is the most difficult to get. And sometimes it's even very hard to get money for sugar, but apart from lack of food and drinks, taking HAART is not a problem." (R27-Defaulted HAART)

"... They told us to eat well. Eat fish, milk, green vegetable and eggs but then what I can afford is what I eat. I think I understood [what I was told to eat]. It's only poverty. If I had money I would buy all they told us to eat."

(R50-Defaulted HAART)

Although failure to obtain and consume nutritious foods was referred to as a challenge to taking HAART, it was rarely cited as the reason for defaulting treatment. Most respondents explained that they ate the type of foods that were available to them. Many commented that they continued consuming the types of foods they had been eating prior to beginning treatment.

"I've been eating the food I can manage to get and I am now fine. That cannot stop me. I will continue taking the drugs and eating the food that I can manage to get." (R52-Taking HAART)

Several participants suggested that provision of food to HAART patients by the government could alleviate the challenge of maintaining a healthy diet. The GTZ programme that had dispensed food to PMTCT-Plus clients was often referred to by the clients as an ideal and beneficial:

"I only ask the government and the GTZ project to again help us like they did at first by giving us food." (R42-Defaulted HAART)

2.2.7 Economic dependence

A shortage of funds to pay for treatment costs was a common theme emerging from the interviews, as demonstrated above. In addition to this, many of the married and/or cohabitating respondents expressed that it was their partners who either provided or controlled these resources. This may be due to cultural factors or the fact that the men, more often than their partners possessed jobs outside of subsistence farming that paid in cash. Many of the clients were dependent on their partners for any money needed for treatment-related costs:

> *"I don't earn anything. We are all looking to my husband. Sometimes he sells a bunch or two of matooke and from that little money we can buy salt and any other needs".* (R29-Defaulted HAART)

In the case of such financial reliance, any expenditure, including treatment-related costs, must first be authorized. This financial dependency influenced a number of clients' decisions to start and continue HAART. In the case of the following client, the fear of losing economic support resulting from abandonment was the reason she withheld her status from her partner and eventually defaulted treatment.

> *"The reason why I didn't tell my husband is that I feared he was going to say that I am the one who has brought the disease and this would have not helped me at all. He would have stopped buying food and drinks and that is why I decided to keep quiet and I used to take my drugs secretly. Because if I told him he would have stopped all forms of assistance to me and maybe would have even sent me away from his home."* (FFGD R6- Defaulted HAART)

Another respondent stated that she was unable to obtain transport money from her husband, thus preventing her from coming to the clinic:

> *"... the man cannot give me money; he would rather use it to drink. He says that he doesn't have money, even when you are sick."* (R16-Never enrolled)

The above quotations indicate that economic dependence of some PMTCT-Plus clients on their partners limits their control over treatment-seeking decisions and ability to begin and adhere to HAART.

2.3 Health Care Services

In exploring the reasons for poor access and acceptance of HAART, it is important that an understanding of patients' experiences of the health care services is achieved. This information will be valuable in providing recommendations to improve the quality of services. As previously mentioned, the PMTCT-Plus programme was initially run by the GTZ from 2003 until 2005. As the PMTCT-Plus programme was handed over to the MOH and Joint Clinical Research Centre (JCRC)-run clinic, clients taking HAART were gradually transferred to the MOH/JCRC- HIV/AIDS clinic, also known as the "Yellow House". Most patients that had defaulted HAART had gained familiarity with the Yellow House services whereas those that never enrolled, and enrolled but never returned had only been exposed to the GTZ-run programme. Clients were therefore questioned about both GTZ and Yellow house services during the interviews. It was found that clients' experiences with the respective programmes were vastly dissimilar.

2.3.1 Conveniences of Services

2.3.1.1 Distance to Buhinga hospital

The PMTCT-Plus and HIV/AIDS programmes in Buhinga are situated in Kabarole District's largest town, Fort Portal. Many of the PMTCT-Plus clients were found to reside in rural areas quite a distance from Fort Portal. Generally, those clients taking treatment resided in urban areas, within Fort Portal municipality, whereas those that never enrolled and defaulted treatment tended to live further away in rural areas. The distances between the clients' homes ranged from two to 30 miles. PMTCT-Plus clients explained that these distances were traveled either by foot, public transportation or a combination of both. Those traveling on foot claimed to walk for up to four hours to receive medical attention and/or treatment. Long distances to the hospital were frequently referred to as a challenge and barrier to starting and continuing HAART treatment.

"It is hard to come this far. This is the reason that I defaulted." (R34- Defaulted HAART)

The problems associated with long distance to Buhinga included difficulty walking far distances and high transport costs:

"My biggest problem is the problem of too much money and the far distance."(R21- Defaulted HAART)

The barrier of treatment-related costs which includes high transportation costs are addressed in the Economics section above.

2.3.1.2 Hospital Hours

The hours of operation for Buhinga hospital are 10am to 4pm. Participants were asked whether or not Buhinga hospital was open at times that were convenient for them, and how this influenced their decision to visit the hospital. All but one of the participants indicated that the hospital was open at hours that were convenient to them. The hospital's operation hours were not described as an impediment to accessing or accepting HAART.

2.3.2 German Agency for Technical Cooperation (GTZ) Health Care Services

All the participants interviewed had attended the GTZ-clinic at some point during their treatment, either to enroll, meet a physician or pick up drugs. To explore clients' views and experiences with the PMTCT-Plus programme health care services, respondents were asked to comment on various features of the services such as wait times, perceived efficiency and quality of care, counseling and their impressions/relationships with staff. Overall, the respondents provided positive feedback regarding almost all aspects of the services received. The GTZ services were seldom identified as the reason for not returning to enroll in the free treatment program.

2.3.2.1 Waiting times

Inquiry was made into the length of typical waiting periods at the GTZ-clinic. Most interviewees responded that the time was short. Rarely was a numeric estimate of wait times offered by the interviewees. Further probing of the respondents showed that patients' wait times ranged from ten minutes to six hours, with most patients stating an average wait time between one and two hours. This waiting period was considered to be insignificant and was not cited as a barrier to taking treatment.

"We used to delay for some few, few minutes; we never used to wait for a long time." (R33- Defaulted HAART)

"We would not wait for long. You would come they attend you and then you would go back home. (R 41- Taking HAART)

Only two of the 46 women interviewed described the wait times at the GTZ clinic as lengthy.

2.3.2.2 Experiences with German Agency for Technical Cooperation (GTZ) Staff

The one-on-one interviews revealed that most patients were extremely satisfied with their interactions with the GTZ staff. Most patients described that they had positive encounters with these health care employees. The respondents often commented that they were impressed by the personability of the staff. Many described receiving a warm welcome and being treated respectfully by the health care workers.

"It was really good, because whenever I would come they [the GTZ staff] would welcome me as their patients and they gave me the treatment that I needed". (R42- Defaulted HAART)

These positive interactions with the staff seemed to have nourished a sense of closeness and trust towards the health care staff among the patients. This trust was reflected in the fact that all clients stated that they had faith that the staff would maintain their HIV status confidentiality.

"I know he/she [GTZ doctor] will keep it [a secret] because nurses and doctors see a lot of things but they don't reveal anything." (R8- Never enrolled for HAART)

The patients interviewed also demonstrated a high sense of trust in the competency of the staff. When asked how knowledgeable they felt the staff to be, all interviewees responded that they felt that the staff knew what they were doing.

" They [the GTZ staff] know their work. They give me the treatment and I am now better than how I was before I started on the drugs". (R5- Never enrolled for HAART)

As stated above, patients generally had positive experiences with the GTZ services and staff. For the most part, the GTZ programme staff were not identified as the reason for failure to enroll or continue HAART. This however was not the case for all the clients interviewed. Six of the 46 clients recalled having negative experiences with some of the staff. Two of these six women failed to return for HAART due to this poor treatment. The reasons provided for rejecting and/or putting off treatment included being neglected or mistreated when their regular doctor was unavailable.

"I've been coming and finding very many people and when [Dr. A is] not there I fail to get somebody to tell my problems. (R15-Never enrolled for HAART)

"Men doctors are welcoming and might talk to you kindly but nurses are not. For example one time I came asking for [Dr. A], one of them asked me rudely that:

"hey, do you belong to us here?" I replied and said "Yes I belong here!" After experiencing this I decided to go away!" (R13- Never enrolled for HAART)

Similar instances of neglect and poor treatment by programme staff were echoed by respondent recounting their experiences with yellow house services.

2.3.3 Yellow House Services

PMTCT-Plus clients taking and defaulting HAART were asked to describe their experiences with the yellow house services and staff. Overall, clients expressed less satisfaction with the services received at the yellow house compared to the GTZ clinic. While there were some patients who were satisfied with the services provided, most had complaints regarding the services and staff. Complaints of negative experiences with the clinic include: long waiting times, poor treatment by health care staff, missing files as well as procedural issues.

2.3.3.1 Yellow house waiting times

The most common complaint made by all respondents regarding Yellow House (YH) services was that of excessive wait times. The complaint of long wait times was made by defaulters and clients taking treatment alike. The interview data indicate wait times to range from two hours to over a day. The interview responses suggest the average wait time in the YH to be approximately four to five hours. Long wait times were a major challenge and in some cases a deterrent to taking treatment:

" We wait so long that I get tired. It makes it difficult to come back that we have to wait again in that long line up." (R43-Taking HAART)

"I also decided to leave the drugs. You can imagine somebody standing in queue going for drugs, you are feeling dizzy, you suffer from morning up to the evening and you end up not even receiving the drugs, for me that is what failed me." (FFGD R7-Defaulted HAART)

Long wait times were cited by many as a reason for missing doses and defaulting treatment. Frustrated by lengthy wait times and failure to receive drugs after waiting the entire day, many patients returned home without their HAART:

"The reason why I stopped taking my drugs is because I would sometimes come and the services at the clinic wouldn't be good. We would spend the whole day at the clinic and you don't even see the nurse and you even end up not getting the drugs and you go back home empty handed. I waited so long and no one was giving me the drugs. I decided to go home."(R20-Defaulted HAART)

Other more persistent clients recounted spending the night in town and returning to the clinic the next day to see the doctor and receive their monthly HAART dosage. Prolonged wait times emerged as a prominent concern in terms of patient satisfaction and barriers to HAART. Throughout the study, participants referred to several situational, procedural and organizational issues that may contribute to these long wait times.

The total number of staff employed at the yellow house is 12, consisting of two doctors, four clinical officers, one site adherence officer, three nurses and two volunteer counselors. These 12 staff members are responsible for providing care to approximately 10,700 patients that attend the clinic. It is obvious that the YH suffers a severe man-power shortage which makes attending to all the patients a daily struggle. This fact was acknowledged in the following participant's interview:

"Here we never used to wait for so long, but up there (yellow house) we wait for so long. Don't you see I've packed food? (laughs) We are very many patients. I cannot start blaming the doctors and nurses." (R50- Taking HAART*)*

In addition to the lack of staff to attend to patients, problems of disorganization within the clinic surfaced. Misplaced or lost files were found to cause delays in the clinic as well as frustration and confusion on the part of the client. The problem of missing patient files was mentioned by five of the 24 YH clients, and even led to a respondent's decision to terminate HAART treatment.

"...they told me my file was lost and I waited until six in the evening and had to spend a night at a friend's home... [the reason I defaulted treatment is] the reason I told you earlier that it's the problem of my file getting lost". (R29-Defaulted HAART)

As shown above, missing files was one reason contributing to the long wait times. Several clients also raised objections regarding procedures for picking up HAART at the clinic, claiming that it was inefficient and time-consuming. Participant #25 explained that patients who come to the clinic in the early mornings are first counseled as a group about HAART and HIV/AIDS prevention. Being that she had taken HAART for some time and had been educated about HAART and HIV/AIDS, she found the counseling was a waste of time and redundant:

"I had to wait from 11am to three pm. They first have to counsel you about the drugs. But I told them that even if I am not counseled about the drugs, I know them. But they still insist that you have to first attend the counseling sessions." (R25- Defaulted HAART)

This point was raised by only one other participant who was taking treatment. The greater part of those interviewed claimed that the group counseling sessions were beneficial in building their understanding about HIV/AIDS and HAART.

Participants also mentioned that having to line up in two separate queues increased wait times. They explained that patients are required to consult with a physician prior to receiving treatment during their monthly visits. This entails both lining up to see the physician and to collect their month's HAART dosage.

"After registration you go to the doctor and the doctor prescribes the drugs for you and then you join the line to go and get your drugs. Sometimes it can be three hours up to even six hours. I come at eight and sometimes I can leave at four."(R 32-Defaulted HAART)

While these long wait times are a nuisance and to some an immense disincentive to taking treatment, many women stated that enduring the long times was an unavoidable necessity. Considering the life-saving effect of HAART, many women explained that even the grueling length of waiting times was not enough to prevent them from obtaining their drugs.

"No [wait times] cannot [affect me]. I have to wait, even other people wait. It's me who wants the drugs for the betterment of my life. I will always wait or even try to come as early as possible so that I have a chance to be chosen earlier and not to wait as long". (R52- Taking HAART)

"No, I can come back [for treatment]; we just have to be patient. We are used to being patient until we get the drugs". (R38- Taking HAART)

Reiterating what has been argued in the above section, the issue of long wait-times was identified as a major contributor to patient dissatisfaction, suboptimal adherence and to some, represented a barrier to continuing treatment.

2.3.3.2 Experiences with the Yellow house Staff

Interviewees were asked to share their experiences with the YH staff. The topic list and manner of questioning regarding the YH staff were identical to those concerning the GTZ clinic staff. The study yielded both positive and negative reviews of the YH staff. Eleven out of the 24 women that had interacted with the YH stated that their experiences were positive; five out of 24 said they hadn't had enough interaction to provide an answer whereas eight of 24 recounted having had negative experiences.

As with the review of the GTZ staff, most respondents demonstrated a high level of trust with regards to the health care staff's ability to keep their HIV status confidential.

"... Those ones at the Yellow house, I know they can keep secrets because they are my friends, even if we meet on the way they can know me as their patient [laughs]." (R35- Taking HAART)

Respondents' remarks also illustrated a strong sense of trust in the staff's knowledge and abilities. Patients' comments rarely suggested that they questioned the staff's abilities, judgments or recommendations:

"Yes [the health care staff are knowledgeable], they know their work. Who am I to start challenging them?" (R41- Taking HAART)

The above quotation was typical of the responses received when asked about their perception of the health care worker's knowledge. This type of answer illustrates the high level of trust and respect that the clients hold for their providers. These women's interviews showed that PMTCT-Plus clients also expect and appreciate a certain degree of respect in return. Feeling welcomed and respected by the health care staff emerged as an important theme when discussing the quality of clients' interactions with clinic staff. When asked to describe their relationship and/or experiences with the health care workers, clients would generally remark on how welcomed and respected they felt by the staff:

"The nurses welcome you as well as their patients. In fact I haven't had any problems. It's now six months since I've started getting drugs from [the yellow house] but I have to tell you I haven't gotten any problems. (R44- Taking HAART)

This response is indicative of the 11/24 women that expressed satisfaction with their experiences with the YH staff. There were however, a few women who were discontented with their YH staff encounters. For some, these negative experiences represented a challenge and barrier to continuing treatment.

Poor communication by staff

The most frequent complaint was that some staff were disrespectful and rude to their clients. Participant #29 recalls a disturbing exchange with a staff member when sharing her ailments and requesting a drug change:

"I explained to the nurse about the first dose they had given me that it had strong side effects on me and that I hadn't completed the dose. I told her that after taking the tablets I would vomit to the extent of even failing to move out of the house and even my heart beats faster and my tongue swells. I told her that if possible she should change the drugs for me. She refused and told me that if I don't want to take the drugs I should go back home and die." (R29- Defaulted HAART)

Another participant compares treatment by the staff in both GTZ and YH clinics, expressing disappointment with her experiences with the YH staff:

"The [GTZ staff] wouldn't shout at you in the midst of other patients as these [YH staff] do, they say "did I give you AIDS?" it is so hurting." (R23-Taking HAART)

Despite the poor treatment and humiliation resulting from the episode described above, participant #23 continued to return to the clinic for HAART. Some clients are not as tolerant of disrespectful treatment and indicated that it either contributed or directly led to their decision to default treatment.

"I told you [the reason I defaulted was that] people [staff] at the clinic are very rough." (R24- Defaulted HAART)

" ... what I am requesting for is that when [the hospital] are giving us these counselors they should select those counselors who are kind to the patients so that he/she can listen to the patients' ailments but not the type of counselors who are very rude and they bark at patients without caring for them. When somebody talks to you in a rude way, even when you are thinking about starting to take drugs you put the idea aside."(FFGD R5- Defaulted HAART)

The above citations demonstrate that empathy and sound communication skills on the part of the staff are important in ensuring that patients remain on treatment. Poor communication and treatment by the staff caused four of the fourteen women interviewed to discontinue their drugs. Another deterrent to taking HAART was neglect of patients by staff.

Staff favoritism and Patient neglect

Neglect by the staff was yet another difficulty encountered by the patients at the YH. This problem of being neglected was mentioned by a greater proportion of defaulters than those who were taking treatment. Staff members playing favorites contributed to the issue of neglect of some patients. Respondents explained that some staff members would cater to friends and acquaintances prior to those whom they did not know, regardless of how long each patient had been waiting. As a result of this favoritism, some patients would fail to receive medical attention and treatment:

"There is one problem I have noticed, when you come here and you are not known to anybody, you can end up going home without receiving drugs". (R31-Defaulted HAART)

"... For example you could come early in the morning and you see they have picked someone who has just come. When you try to tell [them] "Ah, I've been here first" they can [yell] back at you saying "Ah, you both come to the hospital, you think she is not a patient like you? Let me first work on this person and then I work on you". They don't know how to talk to patients." (R25- Defaulted HAART)

Participant #25 had defaulted as a result of failure to receive attention on two consecutive occasions. She explained that because she did not know any of the staff personally, she was ignored. Participant #25 received treatment on the next visit, when she returned after learning a former GTZ nurse that knew her was working on that day.

Participant #44 recalled a similar situation. Being a stranger to the health care workers present at the hospital during her visit, she was continuously referred to other staff members and in the end failed to receive care.

"[The staff] confused me. I talked to one doctor, he said go to the other one, [I went] to the other doctor and he says go to the other one. So they were really confusing me... How can I say it, they were taking patients to be [like] a ball to be thrown around." (R 44-Taking HAART)

This act of favoring patients by some staff members increased wait times among certain patients and can lead to failure to receive, adhere and continue treatment. Four of the 14 defaulters claimed that patient favoritism by staff and susequent failure to receive treatment contributed to their decision to terminate treatment.

It is evident that the manner in which staff treat patients is influential in one's decision to take HAART. Poor treatment by staff can represent the tipping point leading to a patient's decision to default treatment, whether temporarily or permanently. Conversely, as was stated by participant one in the female focus group discussion, respectful treatment by staff may promote optimal HAART adherence.

> *"The way [GTZ staff] served us with kindness, with no discrimination and knowing about how it is for someone suffering from this disease. They understand our problem, even when someone comes to the clinic very disappointed, but [the staff's] loving kindness brings somebody back to normal life, so we are encouraged to go on."* (FFGD R1- Defaulted HAART)

2.4 SOCIAL ENVIRONMENT

2.4.1 HIV/AIDS Stigma

People living with HIV/AIDS (PLWHA) all over the globe have been known to suffer stigmatization by their communities. To elucidate the degree HIV/AIDS stigma and its effect on women's decision to take HAART, a variety of questions pertaining to the topic were addressed. Respondents were inquired about their community's view of HIV/AIDS, HAART and how this affects their ability to take treatment. Responses were mixed, suggesting that a shift in the communities' view of HIV/AIDS, PLWHA and HAART is underway.

2.4.1.1 Community view of HIV/AIDS and People Living with HIV/AIDS

As mentioned above, various perceptions on the community's view of HIV/AIDS and PLWHA were presented. Although almost all of the participants indicated that there were people in their communities who gossip about PLWHA, some also acknowledged the fact that there were others who did not discriminate against or mind people living with HIV/AIDS:

> *"People in the villages no longer talk about people with AIDS now a days. They consider it to be like any other disease and have accepted to live with it, and assume that everybody has it."* (R 17-Never enrolled for HAART)

This sentiment is encouraging as it shows that progress has been made in decreasing HIV/AIDS stigma. However, the interview data shows that HIV/AIDS stigma persists, and is quite prevalent throughout communities. The majority of Respondents expressed that community members frequently gossip about people living with HIV/AIDS:

"You see in the villages when people know you are HIV positive they start talking about you and even your friends can abandon you". (R49 -Never enrolled for HAART)

"Some people make fun of AIDS patients and laugh at them and despise them". (R5- Taking HAART)

Apart from being gossiped about, some respondents claim that they were discriminated against. The following participants explain that they are regarded as already being dead by friends, family and community members since their positive HIV diagnosis.

"When [Health care staff] test you and they find you HIV positive and you go and tell your people at home [family and friends], yes they sympathize with you but at the same times they start looking at you as a problem in the home that is why you see us suffering. Because they know that you are not going to get cured and they say that why should they assist someone who is sick and moreover who is going to die at any time." (FFGD R6- Defaulted HAART)

"[The community] looks at [PLWHA] as people who are dying tomorrow and are less important for the nation."(R31-Defaulted HAART)

Respondents were also asked to provide insight into their community's view of HAART patients. Similar to the above sentiment, participants suggested that some community members view PLWHA as dead despite the fact that they were taking treatment:

"Some people laugh at us saying though we swallow the drugs we shall die." (R51- Taking HAART)

Not all respondents claimed that members of their communities felt this way, and explained that some do see HAART as being beneficial:

"Those who don't understand say that even though HAART patients swallow the drugs, they will still die. Those who understand know these drugs have been helpful to the AIDS patients". (R47-Defaulted HAART)

Three of the of the 46 women interviewed suggested that their community members viewed HIV+ people taking HAART as wanting to conceal and spread their HIV/AIDS infection. An example of a citation expressing this sentiment is provided below:

> *"Other people think that those people who start to use HAART do it to hide themselves so that they can continue infecting others. Some patients do not do what the doctors instruct them to do. That is what others think about people using ARVs."* (R1- Never enrolled for HAART)

These are some examples of the feedback provided by informants regarding their perception of their community's view of HIV/AIDS, PLWHA and HAART. Initially, it was predicted that clients taking HAART would present a more positive view of their community's perception of HIV/AIDS, PLWHA and HAART than those who had never enrolled or defaulted. This was not the case, however as all groups were similar in their variability in responses. Those taking HAART did not indicate a lesser degree of perceived HIV/AIDS stigmatization in their communities than those who were not taking HAART.

2.4.1.2 The Influence of Community HIV/AIDS Stigma on HAART patients

Most of the respondents claimed that the community's view of HIV/AIDS and PLWHA had no bearing on their decision not to start or continue treatment. Many interviewees explained that the decision to take the life-saving HAART was their own and was no-one else's concern. The phrase used most frequently to convey this notion was "It's my life", as in the following quotations:

> *"What people think does not hinder me because this life is mine. Let them talk. I'm not the first one [to have HIV]."*(R36-Taking HAART)

> *"Yes, they will find out [that I am HIV+] but I will continue taking my drugs. It's all about my life; I don't care what other people are saying".* (R39-Taking HAART)

Quotations related to the sentiment "it's my life", such as those above were prevalent throughout most of the interviews. There were however, a few individuals who were concerned about being identified as HIV+. Out of fear of being known as HIV positive, some clients undertook secretive behaviors to conceal from their communities that they were on HAART. These included hiding their treatment card and drugs:

> *"No, I've never seen anyone I know from this end.[at the YH]. I try to hide my card and drugs. How can they know [I'm HIV positive]?* (R23-Taking HAART)

Being that the YH caters specifically to HIV/AIDS patients, any person seen entering the building is immediately identified as having HIV. This association of the YH building with HIV/AIDS patients infringed on women's ability to maintain their status confidentiality.

> *"Everyone knows that the yellow house is for HIV patients and if they saw you going there then they will know that you are HIV positive."* (R42- Taking HAART)

Another participant mentioned that the long wait times at the clinic was problematic in that it increased the amount of time for them to be seen in the YH and spotted by family, friends or community members.

> *"The wait times should be shorter so that people will not see me in the clinic or if it could be like before in the out patients clinic then no one will know for which disease I have come and which drug that I am picking."*(R31-Defaulted HAART)

Due to the fact that being seen in the YH denied patients anonymity regarding their HIV status, a few women were reluctant to be seen in the building. Participant #36 shares her encounter with a neighbor whom she had seen during one of her monthly check ups to obtain HAART. The neighbor was embarrassed to be seen in the YH and fabricated a story to cover up the fact that she was HIV positive.

> *"[My neighbor] never wanted me to know that she has come [to the clinic] for [HAART] and I knew she had come for the medicine. She said "ehhh, [participant 36] someone had sent me to pick [their] drug, now where do I go?" I said "no, you go there you take the receipt and then you take the drug". And I knew it was for her."*(R36-Taking HAART)

Other patients were more creative in trying to conceal their status from the community. The following participant explains that she brings her nephew to the YH with her so that if she is seen, she can tell people that she was escorting her nephew to pick up his HIV drugs.

" ... I always go [to the HIV/AIDS clinic] with my brother's kid in disguise. I take the child and if someone asks, I say I am taking the child to pick up his drugs". (R23- Defaulted HAART)

Fear of being recognized and labeled as an HIV patient by her community led one participant to default HAART. Not only was she reluctant to be marked as HIV positive, she feared that her husband would be identified as having the disease if her secret became public:

"[If people find out my status] it really worries me. Because when the community finds out that I am on HAART, they'll think that my husband is also infected... [People finding out my HIV status] are one of the reasons why I stopped taking my medicine." (R31-Defaulted HAART)

While there were a few participants who told of going to lengths to hide their HIV status, many claimed that it was not difficult to hide from their communities the fact that they were taking HAART. The majority of the women claimed that since they were able to take the drugs from the privacy of their own homes, the likelihood of people finding out was negligible. Furthermore, many respondents explained that even if they were seen taking HAART, people would be unable to determine for which disease the drug was intended:

"It is not easy to know that someone is taking these drugs. When you are in your house, can somebody know that you are taking drugs? No." (R9-Never enrolled for HAART)

"They can maybe think that I'm swallowing drugs maybe for malaria. They won't know that I'm sick of AIDS." (R49-Never enrolled for HAART)

2.4.2 HIV Serostatus Disclosure

The section above describes some women's response to their community's perception of HIV/AIDS and HAART patients. Although some women claimed to be fearful of having their HIV diagnosis discovered by their communities, it was found that the majority of women had disclosed their status to someone. Only three of the 52 women interviewed (interviews and FGDs) had kept their diagnoses to themselves. Most women explain having disclosed their status to someone whom they trusted, most often these were family members. Some shared their diagnosis with close friends. Although the majority of informants indicated sharing their status with another person, a considerable proportion revealed that they had not disclosed their status to their partners.

2.4.2.1 Non-Disclosure to Partner

Non-disclosure of HIV status to clients' partners emerged as a major barrier to accessing HAART. Fear of serostatus disclosure to the respondents' partners was cited as an impediment to taking treatment by all groups not taking HAART, including those who never enrolled, enrolled and never returned and defaulters. Of the 52 female respondents in both in-depth interviews and Focus Group Discussions, ten confessed to withholding their diagnosis from their partners. This did not emerge as a problem among informants taking HAART, as none reported holding back their status from their partners.

2.4.2.1.1 Partner testing and Non-Disclosure

The interview data suggests that these women are more likely to disclose their status to partners who have tested for HIV. Of the ten women who did not disclose their status, eight of their partners had not tested for HIV. The following quotation illustrates how clients' partners' failure to test made serostatus disclosure a challenge.

> *" I did not tell my husband because he refused to go for a check up with me, so I decided to wait to start the drugs because when I tell him he will say I am the one who brought the disease."* (R11- Never enrolled for HAART)

This challenge of disclosure stems from men's refusal to test for HIV, a recurrent theme that surfaced over the course of this study. Interview participants described that their partners/husbands adamantly refused to be tested for HIV:

"On informing [my husband], I also asked him to come and test but he refused, saying that he is not feeling bad and has no complications so I had to leave him alone". (R19-Defaulted HAART)

"I told him that I tested HIV positive and that he should also go and test but he refused. It was when he got in an accident and was hospitalized that the nurse kept on counseling him and he accepted." (R42-Taking HAART)

Having a partner who was not taking HAART also represented a barrier to treatment among some clients interviewed. During PMTCT-Plus counseling sessions, women are informed that HAART is more effective if both partners are ingesting the drug. If only one partner is on HAART, she runs the risk of becoming re-infected with the HI virus and also reducing the efficacy of drug. The fact that their partners were not taking HAART caused the following participants to fail to start and default their treatment:

" As long as I knew my husband would not accept to come to be tested, I feared to tell him and I realized that using these drugs alone was a wastage of drugs because I would be taking the drugs and yet my husband is not taking any drugs so I decided to stop taking them." (R3-Never enrolled for HAART)

Another respondent said:

[The main reason I am not taking HAART is] because my husband refused to test and so it would be meaningless for me to take the drugs while he is not; and the drugs will not work if both of us do not take it. (R 19- Defaulted HAART)

Having a partner that hasn't tested or is not on HAART represents a barrier to taking treatment, and can contribute to a woman's decision to default the drug. Participant 25 reiterates this point in the following statement, suggesting women are more likely to take HAART if their husbands are doing the same.

"Some ladies complain that "ah, for me when I tell my husband he says "ah, you can [take HAART] but for me I will not go there." Like that. I am encouraging [husbands] to take HAART because they [women] are likely to take [HAART] if the husband takes HAART."(R25-Defaulted HAART)

2.4.2.1.2 Non Disclosure resulting from Fear of Relationship Disruption:

Further inquiry and probing regarding non-disclosure was performed to elucidate the reasons for this secrecy. Most respondents explained that they withheld their status from their partners for fear of the repercussions that may ensue. These included fear of being blamed, beaten, abandoned and divorced.

Fear of being blamed:

Among those who did not disclose their status, the majority of women conveyed a concern that disclosure would result in being blamed for contracting the HI virus. A few participants went on to explain that because they were the first to test, their partners would assume that they had been unfaithful and had reason to suspect themselves as being infected. The following citations illustrate this fear of being blamed for bringing the HI virus:

"I fear that he might say I'm the one who has slept around and brought the disease. I fear he will leave". (R11- Never enrolled for HAART)

"For me the reason why I did not tell my husband is that I thought that when he sees me taking the drugs he will say that I am the one who has brought the disease and he will beat me. I was taking the drugs secretly and thereafter said to myself how long will I keep hiding the drugs, and I decided to leave the drugs". (FFGD R5- Defaulted HAART)

Fear of being blamed emerged as a strong motivator for non-disclosure, as being blamed was usually paired with other negative outcomes such as being beaten or abandoned. The fear and anticipation of being blamed described by the respondents is not unfounded. Data from the male FGD (See section 2.7) suggests that some men do suspect promiscuous/unfaithful behavior from those women who have gone for HIV/AIDS testing.

Fear of Violence:

As alluded to in the above quotation, fear of being beaten or having other violent acts directed towards them was a deterrent for sharing one's status with her partner. Participant five from the focus group discussion identifies the fear of being beaten as a major deterrent to disclosing status and taking HAART.

*"Most men refuse to go for [HIV testing]. When you tell your husband that "I was checked and found HIV positive, and you should also go for testing" he will beat you to death. That's the biggest problem." (*FFGD R5- Defaulted HAART)

Another respondent explains:

"When you as a woman you go and they test you and find you with that disease and you go and tell your husband he will say that you are the one who has brought the disease. He will ask you why you have bothered to go and be checked, you are the one who brought the disease and he ends up killing you." (FFGD R1-Defaulted HAART)

Fear of Abandonment and/or Divorce:

In addition to fear of being blamed and beaten, women also declared a fear of abandonment or divorce from their spouse. This fear is not unwarranted, as some participants have described being abandoned by their partners after disclosing their HIV status:

"I told him I was found HIV positive because I was not breastfeeding so he said he couldn't stay with me any longer and he left."(R38- Taking HAART)

Abandonment and divorce by clients' spouses following disclosure of their HIV status was recounted by numerous participants. One participant shared that she was abandoned by two consecutive partners after making her diagnosis known to them. Not all participants are abandoned by their partners, as made evident from the transcript excerpt below:

" He told me that "If you are HIV positive, you know I don't love you", but he wanted to confirm whether or not he was infected and afterwards when that child was also tested and found HIV+, then he accepted to stay with me." (R7-Never enrolled for HAART)

The above quotation illustrates the importance of testing among males, in that it can remove or displace the blame of acquiring HIV that is placed on the woman. It can, as in the above case, encourage couples to stay together and provide each other the support needed to deal with the disease.

Fear of Economic Loss:

The fear of being abandoned and divorced that was mentioned by a handful of respondents was often associated with a loss of economic support. Many of the women explained that they rely on their partner/husband for money, food, shelter and other necessities. Abandonment resulting from disclosure potentially could deprive them of this source:

"The reason I why I didn't tell my husband is that I feared he was going to say that I am the one who has brought the disease and this would not have helped me at all. He would have stopped buying food and drinks and that is why I decided to keep quiet and I used to take my drugs secretly. If I had told him he would have stopped all forms of assistance to me and maybe would have even sent me away from his home." (FFGD 6-Defaulted HAART)

The participant above had defaulted treatment out of fear of being discovered by her husband. Participant eight, referenced below, never returned for treatment for fear that her husband would learn of her status and leave her to fend for herself and her child.

"This child was very young and I knew that if I told [my husband] he would run away from me and leave me suffering with the child. So that is why I fear to tell him." (R8- Never enrolled for HAART)

Respondent eight above, presented an interesting case. Although she feared to disclose her status to her partner, she believed that her husband was aware of her diagnosis, yet had never confronted her about it.

"I think he even knows about [my HIV+ status] now, because at first when I came here when the this child was very young, I told him that they had instructed me not to breastfeed the child and that you should be giving me money for buying milk, so even if he does know, he just keeps quiet."(R8-Never enrolled for HAART)

This description exemplifies the tremendous sensitivity and difficulty in discussing HIV/AIDS diagnosis among partners.

Breastfeeding as a form of Disclosure:

The above quotation also demonstrates another point made by two interview participants during the study. Not practicing breastfeeding is an instant give-away of one's status, as breastfeeding is the standard practice and it is widely known that HIV positive mothers should avoid this type of feeding to prevent mother to child transmission of HIV. One mother argued that this could prevent some mothers from taking HAART.

*"Some [HAART patients] fear continuing [HAART] because they know when they give birth in the hospital there's a tablet they give you, then they tell you not to breastfeed so they fear their husbands would see them not breastfeeding and they will know they are sick and abandon them. This makes them fear to take the drugs" (*R38- Taking HAART)

Participant 38 experienced this scenario first hand. Her husband had become suspicious of her when she avoided breastfeeding her child. After divulging her status to him, he abandoned her and her child.

2.4.2.2 Non-Disclosure of Partner to PMTCT-Plus Client

The interview data revealed that non-disclosure of HIV status to the respondents' partners was a barrier to accessing HAART. It soon became evident that this problem of non-disclosure worked both ways. A handful of participants shared that despite their husbands/partners' knowledge of their own positive HIV statuses, they kept it to themselves:

"I told [my husband I had tested for HIV] and he said that he had also tested and found that he was sick. I got so annoyed and told him to leave me alone because he tested and kept quiet which means he wanted me to die". (R50- Taking HAART)

"When [my husband] came back home he kept quiet but I found his papers and I read them and found out that he was sick. Later I also came and tested."(R51-Taking HAART)

Participant one recounted that her late husband had been diagnosed HIV positive and had been taking HAART for some time, leading her to believe that it was diabetes medication.

"We were [getting along] because he knew I was not aware that he has HIV. At first he was suffering from diabetes and was taking [HAART] because he knew I would think he was taking drugs for diabetes. Later on he was diagnosed for TB and he used to take anti-TB drugs secretly". (R1-Never enrolled for HAART)

This secrecy forced participant one to, in turn, withhold her positive sero-status from her husband. Being that participant one had not told her husband that she was HIV+, she put off starting HAART until after her husband had passed away.

The interview data demonstrates that secrecy breeds secrecy, a behavior that is highly detrimental to the plight to increase patients on HAART and reduce the spread of the HI virus. One would think that due to the immense damage that HIV/AIDS-related secrecy could create, that secretive behavior within families would be chastised. This was not always the case. One participant expressed that her community expected her to withhold her status from her husband and mocked her when she had revealed her status to him:

"Of course those who know about me say, "that one, Mrs. A is a fool because she went to Buhinga to check herself and even took her husband. That is what they are saying, that I should have kept this a secret. That is what most people are saying, that telling other people that you have gone for testing shows that someone is a fool." (R7-Never enrolled for HAART)

The passages above demonstrate that a mutual distrust and lack of communication exists between some couples, which can represent an obstacle to taking HAART.

Lack of communication and distrust can also make practicing safe sex a challenge.

2.4.2.3 Non Disclosure and Safe Sex

During the HAART counseling sessions, PMTCT-Plus patients are advised to avoid unprotected sex in an effort to prevent re-infection and viral resistance to the drug. Interview participants were asked to explain whether or not they were able to practice safe sex and how it affected their ability to take HAART. Most participants responded that practicing safe sex did not constitute a barrier to taking HAART:

"[wearing condoms] is a minor issue. That couldn't stop me because using a condom or not is all the same. There's no difference". (R48- Taking HAART)

Another participant explains:

"No, [having save sex is not a problem],I told him eh that you have to put on a raincoat [condom]. So if you want something you have to put on a raincoat. Ya and I told him the advantages and the disadvantages." (R36- Taking HAART)

Both excerpts above exemplify the type of responses received from the group of respondents currently taking HAART. None of the patients taking HAART mentioned that practicing safe sex as a deterrent to taking the drug. This was not the case among the defaulters, never enrolled and enrolled but never started treatment. Practicing sex was primarily a problem among those who had not disclosed their status to their partners:

"He might find out about [my HIV status] if I want to use a condom. I haven't decided yet since I haven't yet started on the treatment. I still fear him". (R 22- Enrolled but never began HAART)

Another respondent explains that suggesting safe sex may give rise to suspicion in the spouse:

*"Some men refuse to use condoms, so some women fear to be suspected because they would only require to have protected sex."(*R21-Enrolled but never began HAART)

One participant (#22), never started HAART, out of fear that her husband would suspect her of being HIV positive when she requested safe sex. Another theme that emerged surround practicing safe sex is fear of partner's refusal to use condoms. This sentiment was expressed multiple times by different participants. Participant #34 had anticipated that her husband would reject the idea of using a condom and consulted the counselor about the issue prior to starting HAART.

"I asked "if my husband refuses to use a condom what should I do?" They told me that I have to make sure that I sweet talk him so as to use it". (R 21-Enrolled and never returned)

Another respondent claimed that she was having unprotected sex despite taking HAART at her husband's request. Knowing that unprotected sex while on HAART can decrease its efficacy she promptly defaulted:

"I realized that I was wasting time. Because me, I was taking HAART and having unprotected sex. It was a waste of time because I am not supposed to be having unprotected sex while on HAART". (R 31- Defaulted HAART)

She goes on to explain her reasons for not using a condom:

"Condoms can be expensive and the clinic is far to pick free ones. Also my partner does not like to use them." R31-Defaulted treatment

The findings presented above suggest that these women have very little control over their ability to employ safe sex practices, with the final call often being made by their partners. This lack of autonomy over sexual practices was shown to represent a barrier to taking treatment for some women.

The following participant recounts that her husband denied her to start HAART, as it meant changing or stopping their sexual practices.

"After training, I had all the information on the drugs to let me start it [HAART], but the difficulties came when I went home and told my husband. He refused because he had not taken an HIV/AIDS test... [My husband is] afraid to come to test and we can't have sex if I'm on drugs". R19-Defaulted Treatment

In the questioning period following the interview, it was found that participant 19 had misunderstood what was told to her by her counselor, thinking that she was prohibited to have sex while on HAART. She had not realized that using protection (as she had been doing) while taking the drug was an acceptable practice for HAAR T patients. She was immediately issued an appointment to restart HAART.

In addition to preventing the HIV/AIDS virus, protected sex is also commonly used as a method of family planning. Initially, it was expected that the desire to reproduce would be cited as a barrier to taking HAART. Although this was mentioned by one participant as a potential barrier facing other women, none of the interviewees specifically stated that their fertility desires influenced their decision to start or default HAART. Some participants demonstrated an interest in becoming pregnant and voiced questions regarding the possibility of pregnancy while on HAART:

"My question now is if I can have another baby?" (R26- Defaulted HAART)

Another respondent that never enrolled for free HAART was pregnant during the time of the interview. After the interview, she shared that she had delivered two babies after her HIV+ diagnosis and had one more on the way. She said that she intended starting treatment after delivering the baby she was carrying. Both during the interview and afterwards she did not indicate that her fertility desires had affected her decision to take HAART, but rather a lack of funding for transportation.

2.4.2.3 Non-disclosure of status as major barrier to other women

Nearing the end of the questioning period, participants were asked to speculate some of the barriers to taking HAART that were faced by other women. The majority of women responded by saying that spouses played a key role in women's failure to start or continue HAART, highlighting the key points mentioned above. These statements were made by both those who did and did not cite partner non-disclosure as the reason for not starting or defaulting. They mentioned disclosure for fear of being blamed, beaten or abandoned. Examples of these remarks are as follows:

"Those women who have husbands, the most important thing is that they fear to tell their husbands, because they think that if they tell them the husbands will divorce them."(R10-Never enrolled for HAART)

"Most women fear [to take HAART] because they are under the men's roof". (R40-Taking HAART)

"Some women can not take HAART out of fear of being beaten or divorced like I have told you. Some women even run away from their homes because they fear their husbands seeing them swallowing the drugs." (R47-Defaulted HAART)

"...a big number of women fear their husbands and they think that if they will maybe kill them saying that the women are the ones who have brought the disease". (R33- Defaulted HAART)

Although only ten of the 52 women interviewed stated non-disclosure to partners as a barrier to taking HAART, almost all identified this issue as a major factor affecting other women. The passages included in the section above demonstrate that a mutual distrust and lack of communication exists between some couples, which can represent an obstacle to taking HAART.

2.4.2.4 Non-disclosure of Serostatus to family members

The data sheds light on the major effects that lack of disclosure between patients and their partners have on their decision to start HAART. Lack of disclosure to other family members did not surface as a significant barrier to taking treatment. Most participants recounted having disclosed their status to members of their immediate family. The lack of disclosure to one's immediate family that did occur was usually done to prevent the family members from worrying:

"I did not tell the people at home because if my elderly parents get to know that I have the disease they may be too scared". (FFGD 6-Defaulted HAART)

Fear of disclosing or revealing their HIV status to immediate family members did not represent a barrier to taking HAART. A few respondents brought up that they feared their in-laws would become aware of their HIV status and relay this information to her husband.

"I do not want my husband's family to know [my HIV status]. They will blame me and tell my husband that I have the disease". (R2- Never enrolled for HAART)

Most participants indicated that since their in-laws lived in a separate building or in a different region, keeping their status secret from them was neither a concern nor a problem.

2.4.3 Social Support

HIV status disclosure to a family member, partner or friend is essential in the formation of a social support network for the patient to rely on while taking HAART. During the initial enrolment sessions, patients are asked by a counselor to identify a treatment supporter; a person who could provide them with support while taking the drug. Respondents were questioned regarding whether or not they had a treatment supporter, the level and type of support they received, who supported them, how they did this and finally how support would or did influence their decision to take HAART.

As stated in the section above, the majority of participants had revealed their status to another person. It was usually these people who constituted the patient's support system. Most participants responded that they were supported by their partners and/or family members. A few mentioned having friends as their main source of support and one person stated that she was being supported by her sponsors from World Vision. As is to be expected, the three participants who kept their diagnoses to themselves expressed that they did not have anyone to support them while on HAART.

2.4.3.1 Types of Social Support

The respondents described receiving various forms of support. The most common type of support experienced was approval of their decision to be tested and encouragement to take HAART. Respondents expressed feeling more confident and assured in taking HAART when supported in this way.

"They encouraged me and said that I should continue with my drugs. Others said that they know the drugs will help me". (R51-Taking HAART)

Another form of support mentioned was having someone to remind them to take their treatment and meet appointments. This type of support was usually provided by a partner or family member residing with the patient. Respondent 12 describes her husband who supported her in this way.

"He wants me to take the drug so he reminds me to take my pills and reminds me when my appointments are. He has to take them soon as well so we can take them together." (R36- Taking HAART)

Many patients stressed that social support is important especially when one is incapacitated by illness. A support system provides someone to assist patients by escorting them to the hospital or fetching their drugs. Several participants mentioned having someone who does or would perform these tasks:

"[My daughter] cooks and even sometimes when I am not able to come and pick the drugs I will always send her."(R41-Taking HAART)

"[My friend is also on ARVS and whenever we meet we share about our weakness and encourage one another to see the doctor. And when I am unable to come to the clinic for my drugs, I send her and she helps me do I" (R50-Taking HAART)

The excerpt above demonstrates the benefits of knowing someone else that is taking HAART in providing emotional support, and sharing experiences. Having a supportive friend who is also a HAART patient was mentioned by several other participants. Although many participants claimed that they received support in the form of encouragement by family members and friends, most expressed an urgent need for financial assistance. This is illustrated in the following citation:

"I do have my husband to support me by reminding but I have no one to help me with my transport and it is this that stops me." (R21-Enrolled but never began HAART)

The type of assistance most frequently referenced was monetary support. Often the term "support" or "assistance" was interpreted by the interviewees as being solely financial. This portrays the important role finances play in one's ability to take HAART. This is not surprising, as the interview data revealed lack of money as one of the major barriers to taking HAART. Support in the form of financial assistance was usually provided by patients' partners and family members. Participant 50 tells of her daughter who quit school to work in her mother's place and earn the money need for taking treatment:

" I told you that the oldest child stopped school so she looks after the banana plantation and reserves like three bunches of bananas so when it's almost time for me to come to the hospital we sell off the bananas and maybe add on some money which the children have worked for." (R50-Taking HAART)

Financial support was typically used to cover the transportation costs to the clinic. This is in agreement with interview data that suggested insufficient money for transport costs to be the greatest barrier to taking HAART. Participant #28 explains how World Vision supports her by providing transport money:

"[World Vision] encouraged me to take the HAART and said that they'll always assist me with transport whenever I come for my HAART". (R28-Defaulted HAART)

Similarly, participant 39 recalls having some assistance with transport money from a friend.

"My friend helps me in all ways because I started on the drugs soon after I had given birth. She reminded me, went to the doctor with me and helped me with transport a little bit." (R 39- Taking HAART)

In addition to paying for transport to and from the clinic, patients had complained about the difficulty in obtaining the nutritious foods that they were required to eat. Some patient's family and friends provided support by offering food, such as milk, fruit and vegetables from their gardens:

"Even my friends they help me. Others they give me fruit like I have told you and others lend me money for transport and I pay them back". (R40- Taking HAART)

Respondent #38 also described her family to support her in this way:

"[My family] say I should continue and they will also help me with anything they can attend to. This gives me courage because in case I don't have food I can go to my aunt and she will give me a bunch of bananas and this also gives me hope." (R38-Taking HAART)

2.4.3.2 The Importance of Social Support

Many participants described that they had received some type of support, be it emotional or financial. For the most part, participants acknowledged that having social support eased the process of taking HAART and was instrumental in enabling one to take HAART, shown in the following citation:

" When someone has support, and you know that your people are able to support you then everything is easy, because you know that you will get each and everything you need and those who got support after starting the drugs are the ones who are now OK". (R1-Never enrolled for HAART)

Most participants that were not taking HAART claimed that if they had more support (mainly financial) they would be taking HAART. This is illustrated by the citations below by two women who had defaulted their treatment:

"If I had someone to give me transport or maybe bring for me my drugs at home, I would not have stopped." (R47-Defaulted HAART)

"When you don't have support, you don't have anybody to look after you, you are forced by your bad health to start the drugs but you eventually fail to sustain yourself."(FFGD R1-Defaulted HAART)

Similarly, respondent ten cited fear of not having monetary support as a reason for not enrolling in the HAART program:

"Not having financial support scares me to start on the drugs."(R10- Never enrolled for HAART)

The section above elucidates the social context in which these participants live and how these factors affect their decision to start and continue HAART. Respondents explained that fear of disclosure and low levels of social support were products of HIV/AIDS stigmatization.

2.4.4 The role of Education in reducing HIV/AIDS Stigma

Although the majority of respondents spoke of incidences of HIV/AIDS stigma within their communities, about a dozen explained that some people were accepting and did not discriminate against PLWHA. Some interviewees attributed this positive view of HIV/AIDS patients to increased levels of HIV/AIDS knowledge among community members. The following participant suggests that acceptance of PLWHA lies primarily among those who are learned, whereas HIV/AIDS stigma is perpetuated by the ignorant:

"Those people who are literate know what is going on in the world these days and they don't care about those people with the disease and those who are still illiterate try to hide as much as possible, they don't want to be known. Yes, they say those things, we hear them talking and gossiping everyday!"(R10-Never enrolled for HAART)

Education was described by several respondents as an effective weapon in combating HIV/AIDS stigma amongst the population. Numerous interviewees expressed that the decreased HIV/AIDS stigma was a product of the community being more cognizant of the high prevalence of the disease within the population. This high prevalence puts everyone at risk of acquiring the HI virus.

"They [members of the community] know this disease came for everyone. The rich or the poor. So they have nothing they can say." (R50-Taking HAART)

Increased awareness among communities of the high prevalence of HIV/AIDS not only decreases stigma among the community, but also instills a sense of confidence in some PMTCT-Plus clients encouraging them to take HAART. Participant 38 comments that knowing other AIDS patients in her community gave her courage to start HAART.

"At first I was worried, but then around our village there are about five people who are also sick and on these drugs so this made me strong and I was not worried anymore." (R38- Taking HAART)

These citations exemplify the vital role that education plays in decreasing HIV/AIDS stigma, altering societal perceptions of AIDS patients and promoting acceptance and adherence to treatment by PMTCT-Plus clients.

2.4.5 Women and Powerlessness - Health Care Decision Making

To explore the HAART and hospital visit decision-making process in the home, respondents were asked to comment on their level of autonomy when making health care decisions. These questions concerned how health care decisions in the home are made, who is involved in making them, and how this affects or affected their decisions to take HAART.

The interviews revealed that for the most part, male partners are intimately involved in health care decision seeking making within the home, including clients' decisions to start HAART. A lack of autonomy in health care seeking decisions was expressed more frequently amongst those who never began treatment compared to those who had taken HAART. Many of these women communicated that they had to seek permission from their partners prior to making hospital visits, exhibited in the following transcript extract:

"I have to tell him that I am going to the hospital to collect my drugs, so that he authorizes me to come."(R10- Never enrolled for HAART)

For some women, such as participant one, the lack of freedom to visit the clinic on her own will prevented her from starting HAART. She explained that he kept a close watch on her, making it impossible to leave the house to begin or retrieve treatment.

"When he was around, he wouldn't let me move an inch from my home. I couldn't go to the clinic."(R1-Never enrolled for HAART)

Fear of HIV status disclosure compounded this problem of low-autonomy, preventing her from seeking permission to make a hospital visit. Participant one, who was interviewed two weeks after her husband's passing, embraced her new found freedom and spoke of her intention to begin treatment:

"Now he is gone, I can do as I please. I will start the drugs now that he is gone. If he was alive now, I would divorce him so that I could take my drugs. It's all about my life." (R1- Never enrolled for HAART)

In addition to dictating the outcome of health care seeking decisions, it became evident that male partners were usually the ones responsible for home finances. Lack of control over finances by respondents was also found to restrict women's autonomy over hospital visits. Some participants explained that it is their husbands who provide them with the transport money required for travel to and from the hospital:

*"I have to inform him first because he is the one who gives me transport and some money to eat something on the way." (*R3-Never enrolled for HAART)

Lack of financial control on the part of the patient means they can be denied permission to visit the hospital if their partners do not have or refuse to allocate money to treatment-related costs, as is demonstrated in the following quote:

"Yes, sometimes he would refuse because we don't have the money to go all of the time."(R16-Never enrolled for HAART)

Although most women with partners indicated that their husbands had a great deal of control over their hospital visits, only participant one cited lack of freedom over her treatment decision as a reason for not up-taking free HAART.

Statements concerning lack of health care autonomy occurred less frequently among defaulters and HAART patients. Many of these women declared they were either single or were responsible for their own health-care-seeking decisions. When asked to explain why they are able to take HAART whereas other women were not able, responses such as those below often ensued:

"*Most women fail to come to an understanding with their husbands. Me, I am a police woman and I don't stay with my husband and though I was staying with him it wouldn't stop me. Most women fear because they are under the men's roof."*(R40- Taking HAART)

"Me, I have freedom. I don't have a man at home that I'll first ask for permission, not even my father or my mother. I have my time to do my own things". (R36 Taking HAART)

These women's statements convey the idea that empowerment and freedom over their own health decisions eases the process of taking HAART. In this instance cultural gender roles such as acquiescence and dependency may act as a barrier to taking treatment for some women. Another culturally prescribed gender role that was shown to impede treatment concerned women's duties and responsibilities in the home.

2.4.6 Home Duties and Responsibilities

To develop a sense of the respondents' daily routine, participants were asked to describe their daily activities. The overwhelming majority of respondents described activities revolving around the home-domain such as cooking, cleaning, farming ("digging") and care-giving. Participants were asked if and how their responsibilities affected their decisions to take HAART. The majority of participants replied by saying that they could easily forgo their home duties to come to the hospital.

"There's nothing better than life. I have a lot of work to do at home but when it's my day to come to the clinic, I leave everything and first come to the clinic." (R51-Taking HAART)

Respondent 52 states:

"I don't have any other jobs maybe digging, cooking, fetching firewood and water but that cannot stop me from coming to get my drugs." (R52-Taking HAART)

The prevailing disposition was that home duties were easily abandoned if the need for hospital visits should arise. Care-giving to family members was the only home-duty that some participants described to hinder their ability to visit the clinic. This barrier was described by two of the participants interviewed:

"...sometimes you have a sick person who you can't leave alone to go to the hospital."(R31-Defaulted HAART)

"The biggest work is that of taking care of my lame son because there are times when I can't even leave home". (R29-Defaulted HAART)

Respondent 29 above explains how the competing duty of care-giving can represent a conflict to hospital visits. Leaving children behind was predicted to be a significant barrier to accessing treatment by most mothers. Interviews indicated otherwise, as participants explained they were able to leave children at school, with family members or neighbors during their hospital visits. Young children often accompanied the mother to the hospital.

The data presented above suggests that some culturally prescribed gender roles such as subservience and care-giving can represent a challenge to taking HAART. Another factor influencing women's ability to take HAART was their knowledge and beliefs of the drug.

2. 5 HAART KNOWLEDGE AND BELIEFS

To explore the level and type of HAART knowledge possessed by PMTCT-Plus clients, respondents were questioned regarding their knowledge of HAART. The aim of this questioning was to explore whether the respondents' possessed a level of HAART knowledge sufficient to make informed decisions about taking HAART. They were asked to explain what they understood in terms of the benefits, drawbacks and side effects of the drugs. Inquiry was also made into the source of their information, what was learned from these sources and how this knowledge influenced their decisions to take the treatment.

2.5.1 Sources of knowledge

When asked to comment on the sources of HAART knowledge, the answers were wide-ranging and varied. It became evident from the respondents' answers that Kabarole's citizens are informed about the existence of HAART. Sources of HAART knowledge listed by respondents included: One-on-one and group HAART counseling sessions at the yellow house, antenatal counseling sessions, radio shows, word of mouth, newspapers, workshops and outreach programs.

2.5.1.1 Counseling

The interview respondents explained that they are presented with multiple counseling sessions during their encounter with the PMTCT-Plus programme. Women are first counseled in antenatal classes where they are informed about the availability of free HAART for HIV positive mothers post-partum. Women are not provided with detailed information regarding HAART at this time. Following delivery, women are again told about the availability of free HAART and given an information letter written in both Rutoroo and English to take home and read. Upon returning for enrollment, women are fully counseled on HAART.

Counseling Content and Length

Respondents shared the type of knowledge that was imparted to them during the HAART counseling sessions. The following transcript passages illustrate the type of information extracted by participants from their various counseling sessions:

"They told me to always swallow the drugs in time and never to miss. They even advised me not to conceive again". (R52-Taking HAART)

"the drugs they weaken the virus and then make our antibodies strong but when you don't follow instructions or miss for some days without swallowing then the virus become stronger and weakens the antibodies." (R 38- Taking HAART)

"The doctor taught me again and again and every time we come back for drugs they again told us about the drugs. So we understand." (R34- Defaulted HAART)

"They told that we should always swallow the drugs on time and I should never miss any days without swallowing that because if you miss, then this virus will get stronger and then I again fall sick. Also they told me that I shouldn't drink alcohol or smoke and that if I have a man we should have safe sex. That's what they taught me". (R50-Taking HAART)

"We were advised to get something to keep us busy. We were also advised to eat foods that were rich in vitamins, like avocados, and tomatoes. We were told not to use any medicine without first showing it to the doctor." (R30-Taking HAART)

Most respondents felt they understood about HAART from the counseling sessions. As indicated above, they reported being counseled regarding dosing schedules, family planning, safe sex, adherence, the benefits of the drugs and nutrition among others. As respondent #30's comment illustrates, women are discouraged from taking medicines (such as traditional medicines) to treat their disease.

Respondents were asked if they had been or were using traditional medicines or any other type of medications in lieu of HAART treatment. All of the patients responded that they had not taken any traditional medicines. A few participants mentioned that they had been taking cotrimoxazole (septra), an antibiotic to fend off opportunistic infections that had been prescribed to them by their physicians.

Comprehension of Counseling Information

The respondents were informed about how HAART works, how to take the drug, to eat a balanced diet, the possible side effects and how to handle them as well as how to prevent transmitting the virus by practicing safe sex. The majority of clients stated that the counseling sessions were beneficial and that they understood what was taught to them. Only four out of the 26 participants that had begun treatment (Taking and defaulting) said that they had not fully understood the information delivered to them.

Both of the participants that had enrolled and never began treatment indicated that they had not understood what was being taught in the counseling sessions.

Respondents were asked about the length of the one-on-one counseling sessions and the answers ranged from thirty minutes to two hours. Most participants recounted their one-on-one counseling sessions to be an hour in duration. This time was indicated to be sufficient to cover the information required to take HAART properly.

"It took a lot of time, we had Dr. A, he was very good, he would explain again and again until he made sure that one has understood". (R40-Taking HAART)

The quotation above is typical of patients' reviews of the one-on interviews. Only one participant complained about the quality and length of her counseling session, due to the high volume of patients.

"[The counseling] only took a few minutes because the clients were many".

(R23 – Taking HAART)

Most participants articulated that the group counseling sessions held at the yellow house were beneficial in enhancing their understanding and ability to take HAART. A lack of knowledge regarding HAART was not cited as a contributor to their decision to default treatment, as stated by respondent one in the female focus group discussion:

"We understood the things they taught us and we were able to do them as told but the problem was that some of us were not capable, that is the only problem." (FFGD R1- Defaulted HAART)

In addition to explaining and evaluating the counseling sessions, participants were asked to provide suggestions on how counseling could be improved. The majority of participants expressed that they were satisfied with the counseling and it need not be improved. Participant #28 suggested that the information and manner of its delivery should be simplified to ease comprehension of the subject by patients.

"You should add more things in the counseling session so that women can understand better...Make the teaching easier so that more people can understand what is being taught". (R28- Taking HAART)

Other respondents also suggested that the frequency of counseling be increased so as to refresh patients' HAART knowledge:

*"For me I am saying that the hours were not enough. It would have been better if they were teaching us every day and they would keep reminding us on what we have forgotten." (*R3-Never enrolled for HAART)

Another suggestion raised by respondents concerned the counselors themselves. The issue of suboptimal treatment by health care staff was addressed in detail in section (See Section 2.3.2.2 and 2.3.3.2). A handful of respondents claimed that some counselors were rude and lacked empathy, as is demonstrated by the following quotation:

" What I am requesting for is that when [the hospital] are giving us these counselors they should select those counselors who are kind to the patients but not the type of counselors who are very rude and they bark at patients without caring for them. When someone talks to you in a rude way, even when you are thinking about starting to take the drugs you just put the idea aside." (R5-Never enrolled for HAART)

For the most part, respondents expressed that the information obtained during counseling sessions was clear and beneficial. Very few stated that they lacked the information needed to take and continue HAART and none referenced lack of HAART information as their reason for defaulting treatment.

2.5.1.2 Radio

Public Health advertisements and other radio shows broadcasted over Kabarole's "Voice of Toro" radio-station emerged as the major source for HIV/AIDS and HAART information among PMTCT-Plus clients. Almost all clients claimed having heard about HAART on the radio prior to their counseling sessions. Some participants explained that radio shows represented a cue prompting them to test for HIV:

"Yes, I used to hear it over the radio that people should go to the hospitals and get tested. There's free medication, especially for pregnant women. So when I was pregnant I decided to come and I am now on treatment." (R52- Taking HAART)

As indicated above, the HAART information played over the radio functions to inform and encourage women to come to the clinic for free HAART. Participant #25 shared that the HAART radio advertisements facilitated the disclosure of her HIV status to her partner and was used to convince him to test for HIV.

"After the counselor told me I was positive, I went home and I told him. By that time that advertisement was on the radio almost every minute. And I said to him, you are hearing that advertisement, let's go together and we test. I told him that I was positive. We went together and we tested us again." (R25- Taking HAART)

Apart from informing the public of the availability of free HAART, other information about HAART relayed through the radio. Respondents recounted having heard various types of information regarding HAART including patient testimonials about the benefits of HAART:

"I hear people over the radio testifying that HAART has worked for them even others I see them when they came the first time they were so weak but now they are stronger, even me myself I came when my CD4 was too low but now it has increased and this shows me that the medicine is working." (R42-Taking HAART)

"I heard this person over the radio. He said that he was 35kgs before HAART and after taking it, he increased to 68kgs." (R31- Defaulted HAART)

Respondents also accounted having heard other types of information about HAART, such as how to deal with potential side effects from the drugs, and how the drug works on the virus:

"... on the radio they say if one gets any problems you should come back and see the doctor." (R49-Never enrolled for HAART)

"Me, I usually listen to the radio programmes. I heard that people should not suffer especially those in villages they should go to hospitals. There's free treatment for HIV/AIDS but then this treatment does not cure AIDS it only weakens the virus and people live longer." (R51- Taking HAART)

The interviews suggest that the radio is an effective method for dissemination of HAART knowledge, informing the public of its availability and efficacy in HAART patients. Aside from its ability to reach a wide audience, the radio represents an important source of HAART information because the messages it delivers is relatively reliable, and can act to dispel the myths and misconceptions about HAART that are circulated by word of mouth within communities.

2.5.1.3 Word of Mouth

Another major source of HAART knowledge mentioned by participants was word of mouth. Apart from the radio, community dialog surrounding HAART was the second most common source of HAART information for those who had never been counseled.

Many participants reported having heard about HAART from people talking in their villages and communities. This information was usually presented by community members gossiping about others they suspect or know to be on HAART. In some cases, HAART information spoken by villagers is accurate, but it was found that very often misinformation and misconceptions about HAART held by clients were derived from these sources. An example of this is presented in the quotation below:

"Some [people] are saying that they see people taking it and from being bedridden they become OK. Others say that it makes you die faster." (R30-Taking HAART)

"[People in the village] say that drugs make you lose energy, and then you die. That's what they say."(R16-Never enrolled for HAART)

The participants conveyed that most HAART patients in their villages fear to share their treatment status and details with other community members out of fear of being labeled as HIV positive. This may represent a setback to increasing HAART knowledge among communities as patients taking HAART can be reliable source of HAART information. Respondents mentioned that although they were not told about community members' status, noticing drastic health improvements usually suggested that one was an HIV patient taking HAART.

"I see [HAART patients], those who have been very weak have regained their strength, and those with small, small diseases have been reduced and they continue doing their normal activities. That's why I say the drug is effective."

(R1-Never enrolled for HAART)

Participant seven reiterates a point made by the previous respondent on the benefit of seeing a patient's improvement on HAART. It encourages AIDS patients to initiate and adhere to treatment:

"They talk about us as taking HAART but it helps after seeing someone who is on drugs improving after taking these drugs. Comparing the situation he was in at first, others change their attitudes and they say, "you see we have been refusing to take these drugs, you look at so and so and how he has improved on these drugs", that is what they say and most of them are going to come out and start on these drugs." (R7-Never enrolled for HAART)

Apart from observation of HAART patients in their communities, many respondents looked to family members and close friends on treatment as their main source of HAART information. These experiences were usually positive, promoting the acceptance of HAART use among these people.

"I have seen a good example of my husband and [my daughter]. Had [my daughter] not started taking drugs, she wouldn't be alive by now. But after starting on the drugs, you see she is alright." (R7-Never enrolled for HAART)

"[My friends taking HAART] said that it is helpful and that they used to be sick but now they are very fine."(R34-Defaulted HAART)

These passages imply that knowing and talking about HAART use with a patient on treatment is an excellent source of HAART knowledge. People are able to witness first-hand the benefits and efficacy of HAART in treating HIV/AIDS, encouraging them to begin the treatment themselves if necessary.

2.5.1.4 Television and Print Material

Being that HIV/AIDS information is extensive in Ugandan media such as television, newspapers and magazines, it was anticipated that these would be frequently referred to as information sources among respondents. This was not the case however, as very few mentioned television or print material to be their source of HAART knowledge. Only one participant of the 52 interviewed claimed she'd read about HAART in the newspapers. Illiteracy and lack of money to purchase televisions, newspapers and magazines may explain why very few people recognize television and print material as their source of HAART information.

2.5.1.5 Workshops and Education in villages

Two participants mentioned that they were sensitized in their villages about the drug by health care personnel or had attended a workshop about HAART.

"People would come to the villages sensitizing people saying there was free medication that people should go and be tested for HIV, especially pregnant women". (R40-Taking HAART)

Although workshops and sensitization programs are excellent sources of HAART information, it seems that very few respondents had been exposed to this type of education.

2.5.2 HAART knowledge among Defaulters and Patients taking HAART

The interview data demonstrated that, for the most part, the knowledge level among defaulters and patients taking HAART to be considerably high. Almost all participants possessed an understanding of HAART sufficient to take the treatment correctly. The majority of patients were able to explain the benefits and side effects of HAART, how the drug worked in general terms and the treatment routine.

All respondents indicated that they believed that HAART was effective in treating HIV/AIDS. The basis for this strong faith in the drug arose from counseling sessions, witnessing others taking HAART as well as personal experiences on the drug. The majority of respondents referred to their experiences improving on the drug as their primary reason for belief in HAART efficacy:

> *"I believe [HAART works] even more when I started them. The complications I had were very severe. Many have gone, with remaining only one complication. That, and I have gained more [weight]."* (R36-Taking HAART)

> *"[HAART] is helpful because by the time I started HAART my hair was falling off from my head and I was too weak but now I am very OK."* (R32- Defaulted HAART)

All defaulters and HAART patients were also able to explain the risks and side effects associated with taking the drug. Inquiry regarding the consequences of defaulting HAART was made, to assess whether participants were aware of these factors when deciding to terminate treatment. Most patients made it clear that they were aware of the risks, but had not choice but to default treatment. Participant #7 explains that although she defaulted, she was aware that it would be detrimental to her health and/or the efficacy of the drug. She previously mentioned that what forced her to default was a lack of money for transport.

"For me I am asking if I start taking drugs again, don't you think I will get side effects because I heard that when you stop taking the drugs and then you start again, you could die? Will this happen if you start taking the drugs or will be no problem? That is my question." (FFGD R7- Defaulted HAART)

This excerpt demonstrates that participant #7 was aware of the seriousness of defaulting her HAART, however may hold some misconceptions regarding the severity of side effects (death) experienced when restarting. Most other defaulters interviewed demonstrated that they were aware of the negative consequences of defaulting treatment. It seems that despite being aware of the severity of defaulting HAART, circumstances leave these clients with no other choice.

Overall, HAART patients and defaulters were shown to possess a sufficient level of knowledge needed to take and continue treatment and were aware of the benefits of HAART and the risks associated with terminating or temporarily stopping the drugs. Low HAART knowledge was rarely cited as a reason for defaulting treatment among these two groups of PMTCT-Plus clients.

2.5.3 HAART Knowledge among Respondents Who Never Enrolled for HAART

All participants including those taking HAART, patients who defaulted HAART , those who never enrolled as well as those enrolled and never returned for treatment were asked the same questions to assess HAART knowledge. The interview data shows a marked disparity in HAART knowledge between those who had started HAART and participants that never enrolled. Unlike respondents who had enrolled in the free HAART program, patients who had never enrolled were not exposed to the one-on-one and group counseling sessions. A handful of participants attributed their lack of HAART knowledge to the fact that they had not been counseled about HAART, as respondent 12 expressed below:

"I didn't go back [to enroll] so I haven't been counseled about this drug yet. So how can I know [about HAART]?"(R12- Never enrolled for HAART)

Although these patients had not been specifically counseled about HAART, they had been provided with information regarding the drug. During registration sessions, clients are given a pamphlet containing HAART information to take home and read. This may have been useful to some participants; however it was observed that many of women interviewed were illiterate. In addition to this, fear of being identified as HIV positive by others discourages women from bringing home and reading their information pamphlet. Participant #27 confessed that although she was given papers, she discarded them out of fear that someone would come upon them and discover her diagnosis:

"Doctor I won't lie. I haven't kept those books for fear that someone will come and read them. They will find out what I am...The information was there but I didn't read it". (R27-Never enrolled for HAART)

Being that these women had never attended HAART counseling, they relied on other sources such as the radio and casual village conversation about HAART for their information. This led to incomplete or misunderstanding of the treatment in many respondents.

When asked whether or not participants believed in the efficacy of HAART, the majority responded positively. Of the 19 participants that never enrolled, five claimed they were unsure if HAART was effective in treating HIV/AIDS. Other questions, such as the side effects, drug routine, length and frequency of HAART dosing were answered with less confidence. There were a few participants that expressed not knowing anything about HAART:

"I don't know anything about these drugs but I would like to be told about them." (R1-Never enrolled for HAART)

"I don't know anything about HAART but it can force me to come and ask if you give me those drugs how I can take them. You explain to me so that I can understand." (R13- Never enrolled for HAART)

Despite the apparent lack of HAART knowledge by many of these participants, most expressed a keen interest in learning more, as demonstrated by the above excerpts.

2.5.4. Misconceptions about HAART

Several popular misconceptions regarding HAART surfaced over the course of the study. These misconceptions were held largely by respondents who had never enrolled for treatment as well as one or two participant who were taking and defaulted treatment. The most popular misconception mentioned by respondents was that taking HAART can make a patient weak thus impairing their ability to work:

"Others [in the village] are saying that when a person starts on the drugs, others get a skin rash on the face and others are weakened by those drugs so much that they cannot do any heavy tasks, they are saying all those things in the villages there." (R10- Never enrolled for HAART)

"...other people say that after taking the drugs, you cannot do heavy work. It needs you to rest, and for me staying still without doing anything will not be of any help to me because of my children. Some of the children I have don't have their second parents, it's like I am their mother and their father. And now if I take these drugs and I do heavy work, I think I will become weaker and weaker."

(R8- Never enrolled for HAART)

"Others are saying that when a person starts on the drugs, some get a skin rash on the face and others are weakened by those drugs so much that they cannot do any heavy tasks, they are saying all those things in the villages there."

(R14 - Never enrolled for HAART)

The origin of this misconception could be the temporary feeling of tiredness that some patients experience when first initiating HAART. The responses received imply that some participants think this state of weakness is a permanent effect of HAART. Being that the majority of women support their families by means of "digging" in their gardens, physical weakness in effect compromises their ability to support themselves and their families. For this reason, several participants decided to avoid beginning HAART. Another misconception expressed by several participants is that HAART can kill its patients, illustrated by the quotations provided below:

"Now you see that if you are taking drugs you can die there and then... I have to control myself and look after my kids to see that they've grown, work for them, and build for them. Now you see my land is not progressing, we want to build. Do you want to kill me there and then?" (R13-Never enrolled for HAART)

*"I hear when you take this drug you die faster". (*R11- Never enrolled for HAART)

"Others fear the drug. They say that drugs make you lose energy, and then you die. That's what people say". (R16- Never enrolled for HAART)

Respondent sixteen's quotation reiterates a point made above, that misconceptions regarding HAART are often perpetuated by gossip or casual conversation about HAART in villages. Misconceptions such as these impede PMTCT-Plus' initiative to increase the number of women on HAART by instilling fear in patients. Respondent #13 cited fear of HAART as a reason for not starting the treatment.

"For me I have told you, what puts me off is that I fear the drugs." (R13-Never enrolled for HAART)

2.5.5. Gaps in Knowledge

In addition to these misconceptions, some gaps in HAART knowledge were identified. Gaps in knowledge were assessed primarily by the type of questions that were raised following the interview and FGDs. This information was classified as a knowledge gap rather than a misconception as it represented a lack of knowledge rather than misinterpreted information.

The most common HAART question asked by patients was whether or not it cures AIDS patients. This question was raised by members of all groups interviewed including those who never enrolled, defaulted as well as those taking treatment.

"The only question is as we continue taking these drugs, shall we at one time get cured or what is the end result?" (R35- Defaulted HAART)

"What I want to know is do these drugs totally cure AIDS?"(R32-Defaulted HAART)

A similar question regarding the outcome of HAART treatment on children was asked by participant #40:

"Now my question is about these children we gave birth to that are HIV positive. What will happen to them, will they at one time get cured or what?"(R40-Taking HAART)

Although this question was asked multiple times by a handful of respondents, there were others whose comments indicated they were aware that HAART does not cure but only treats AIDS patients.

Another area of HAART knowledge unknown to some respondents surrounded the option of pregnancy while on the treatment. Three participants expressed a desire to have more children but were unsure whether or not they could become pregnant while on HAART:

"The question is what do I do if I want to have another baby?" (R20- Defaulted HAART)

Subsequent to the interview, respondent #20 met with a doctor to discuss the possibility having another child.

2.5.6 Effect of low HAART knowledge on acceptance of HAART

The section above describes that knowledge gaps and misconceptions exist among some PMTCT-Plus clients. Respondents were asked to explain how their level of HAART knowledge influenced their decision to take HAART. Participants who never enrolled in the free treatment program expressed that they may have begun treatment if they were more informed about HAART:

"Maybe if I understood [more about HAART] I would come back." (R21-Enrolled but never began HAART)

*"If I knew that the drug was treating me or maybe it would make my life be longer, then I would start on the drugs". (*R10-Never enrolled for HAART)

The above quotations demonstrate that knowledge of HAART and its benefits can be critical in prompting patients to take HAART. Insufficient HAART knowledge can also engender fear towards the drug, preventing uptake of the treatment, as expressed by respondent #16:

"[Not knowing about HAART] can make me fear because I've not understood this drug... If I knew about the drug, then there would be nothing to fear." (R16-Never enrolled for HAART)

2.6 PATIENT FACTORS:

Apart from external factors previously mentioned such as economics, health care and social environment, other patient-specific variables were found to impact one's decision to take HAART. These included the patient's current health state and experiences of side effects on HAART.

2.6.1 Patient Physical Health and Disease State

To qualify for the free HAART program, PMTCT-Plus clients must be found to have a CD4 serum count of 200/mm^3 or less. A CD4 serum count less than 200/mm^3 is indicative of a weak immune system. Despite possessing low CD4 counts, many of the respondents claimed to still feel healthy and therefore saw no need to immediately begin treatment. They explained that they were holding off HAART when they felt unwell. Over half (11/19) that hadn't enrolled for free HAART expressed this sentiment. The excerpts below illustrate this notion:

"I will start this drug in the future because I will become sick". (R11- Never enrolled for HAART)

> *"My father is saying, "why can't you go and start on the drugs?" and I tell him "how can I start on the drugs and yet I am not yet bedridden and I have not felt anything and not seen any symptoms, and now I if I start on these drugs as I am seeing people feeling dizzy, I will not be able to dig, but if I feel anything I will go and start on those drugs".* (R7-Never enrolled for HAART)

Respondent #11, who cares for two HAART patients, her husband and daughter, indicates her plan to delay treatment until she had reached the point of becoming bedridden. This was an interesting concept that was restated multiple times by other participants. To optimize the efficacy of HAART, patients are advised by their health care providers to initiate treatment prior to the onset of severe health deterioration. It seems, however, from participants' responses that many patients regard being bedridden as the expected point of entry. Respondents often referred to friends, family and acquaintances that initiated treatment after reaching the point of being bed-ridden. This common practice may lead other PLWHA to believe this to be the most suitable time to start HAART. One respondent raised a question regarding the treatment initiation point:

> *"Now is that drug started on by that person who is on his/her deathbed or someone who is still healthy?"* (R9-Never enrolled for HAART)

This question may signal yet another HAART knowledge gap among PMTCT Plus patients. While unfamiliarity with standard HAART procedures alone may lead to a delay in treatment, it seemed that economics may also play a role. Several respondents' statements indicated that stalling treatment until absolutely necessary may be, in part, an effort to save money.

> *"It depends on how I feel in my life. What can force me [to start HAART] is money because when I have money and feel that I'm not OK, then I can start."* (R14-Never enrolled for HAART)

> *"It is very far to go [to the hospital] and all the times though I try by all means I cannot make the money to come to the hospital. Furthermore, I am not feeling too sick so I don't need to come."* (R15-Never enrolled for HAART)

The process of weighing one's physical state against the availability of finances when making a decision to take HAART was repeated by multiple other participants.

2.6.1.1 Adverse Reactions to HAART

As HAART is often associated with a number of harsh reactions or side effects, it was expected that a large number of respondents would cite negative reactions to the drug as a reason for defaulting. As previously mentioned, fear of side effects, or a misconception of side effects acted as a deterrent for participants to enroll in the free HAART program. Contrary to what was expected, very few respondents claimed that experiencing HAART side effects influenced their decision terminate treatment. Of the participants from the interviews and focus groups combined, only two of the 21 participants claimed that side-effects caused them to halt treatment. One of these participant's comments are included below:

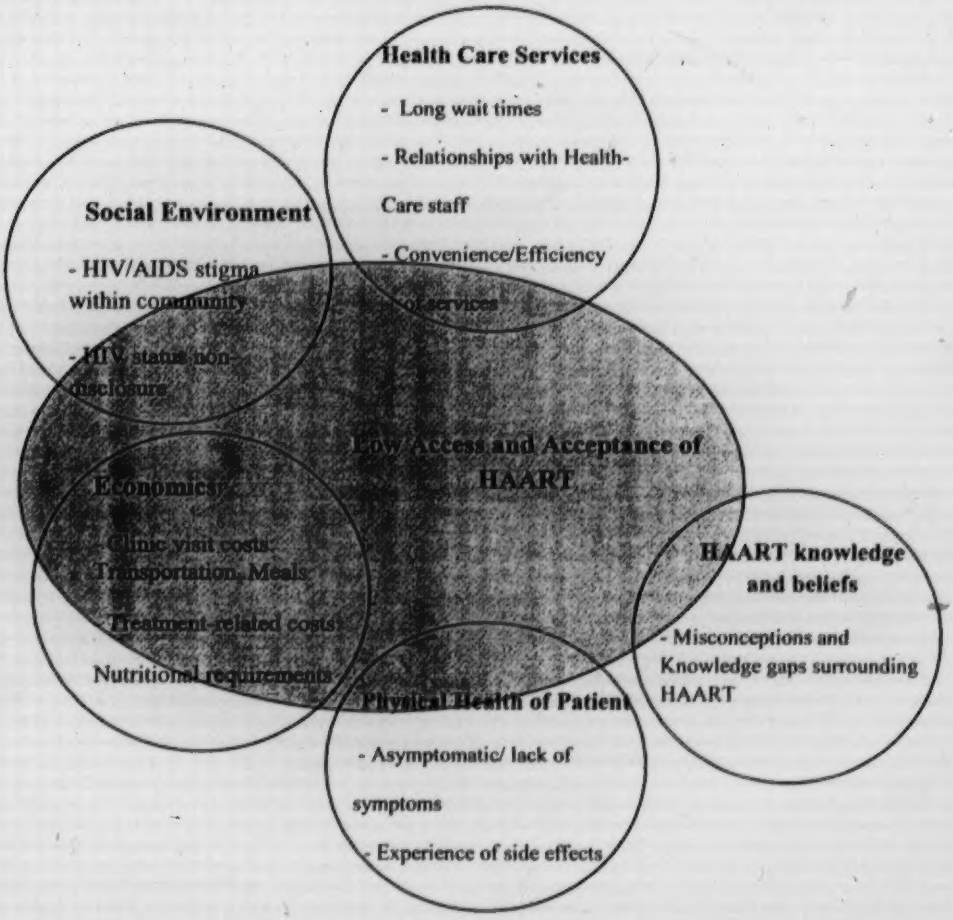
"The truth is that I didn't take the drugs. The first time I tried taking them I got side effects and when I talked to another doctor about the side effects he gave me other tablets and told me to first leave the ARVS".(R29- Defaulted HAART)

Participant #29 had defaulted due to HAART side effects and has never restarted the drug. While other participants recounted experiencing side effects, most revisited the doctor to switch to a different combination of antiretroviral drugs.

The results section above elucidates the numerous factors that influence women's decision to take HAART. The factors contributing to low access and acceptance of HAART by PMTCT-Plus clients described above have been summarized in the diagram below. Reiterating what has been elucidated in the section above, there is considerable variability between individuals in their reasons for not up-taking HAART. A single or combination of several factors and pathways can lead to low access or acceptance of HAART by PMTCT-Plus clients.

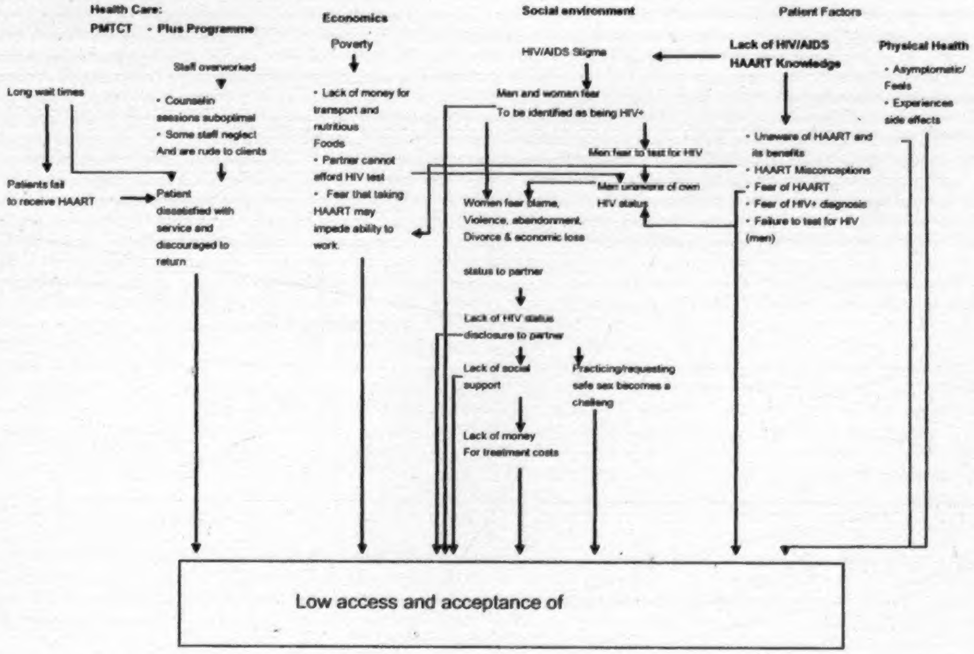
The diagram below illustrates the various factors contributing to low uptake of HAART. The degree of overlap between the category circles and the outcome circle representing low access and acceptance of HAART signifies roughly the influence each category has on PMTCT-Plus clients' decisions to uptake HAART as expressed by the respondents.

Figure 2.1 Diagrammatic representation of study results: Factors leading to low access and acceptance of HAART


Health Care Services
- Long wait times
- Relationships with Health-Care staff
- Convenience/Efficiency of services
Social Environment
- HIV/AIDS stigma within community
- HIV status non-disclosure
Low Access and Acceptance of HAART
Economics:
- Clinic visit costs: Transportation, Meals
- Treatment-related costs:
Nutritional requirements
HAART knowledge and beliefs
- Misconceptions and Knowledge gaps surrounding HAART
Physical Health of Patient
- Asymptomatic/ lack of symptoms
- Experience of side effects

The figure above outlines the themes associated with low uptake of HAART. The following framework presented below outlines in greater detail the findings from this study. The diagram describes how the various categories act and interact to lead to the result of low access and acceptance of HAART by PMTCT-Plus clients, as described by the participants themselves. As above, the various categories are grouped by themes (e.g. Social Environment, Economic Factors, Patient Factors, Health Care Factors, Lack of HIV/AIDS and HAART various successive events and pathways that lead to low access and acceptance of HAART as described by study participants. As explicated in the results section above, a single or a combination of several of these pathways can contribute to poor HAART uptake in a PMTCT-Plus client.

Figure 2.2 Conceptual framework of factors leading to low access and acceptance of HAART by PMTCT-Plus clients in Kabarole District, Uganda.



Health Care:
PMTCT - Plus Programme
Economics
Social environment
Patient Factors
Poverty
HIV/AIDS Stigma
Lack of HIV/AIDS
HAART Knowledge
Physical Health
Staff overworked
• Asymptomatic/
Feels
• Experiences
side effects
Long wait times
• Counselin
sessions suboptimal
• Some staff neglect
And are rude to clients
• Lack of money for
transport and
nutritious
Foods
• Partner cannot
afford HIV test
• Fear that taking
HAART may
impede ability to
work.
Men and women fear
To be identified as being HIV+
Men fear to test for HIV
Men unaware of own
HIV status
• Unaware of HAART and
its benefits
• HAART Misconceptions
• Fear of HAART
• Fear of HIV+ diagnosis
• Failure to test for HIV
(men)
Patients fail
to receive HAART
Patient
dissatisfied with
service and
discouraged to
return
Women fear blame,
Violence, abandonment,
Divorce & economic loss
status to partner
Lack of HIV status
disclosure to partner
Lack of social
support
Practicing/requesting
safe sex becomes a
challeng
Lack of money
For treatment costs
Low access and acceptance of

2.7 MALE FOCUS GROUP DISCUSSION RESULTS

The study data revealed that husbands/partners have a tremendous influence on PMTCT-Plus clients' decisions to begin and continue HAART. Several barriers, such as serostatus non-disclosure and lack of social support revolved around partner attitudes and involvement. Male perspectives on these topics were sought in order to supplement the female interview data as well as achieve a holistic understanding of these barriers. The topics addressed in the male focus group discussions included: level of HAART knowledge, issues surrounding lack of male testing, low HIV status disclosure among partners and social support. Possible causes and solutions for low uptake of HAART by PMTCT-Plus clients were discussed. The data extracted from both urban and rural interviews revealed the views among men in both urban and rural areas to be very similar. There were no obvious discrepancies in the views expressed among urbanites and rural participants on the topics addressed.

2.7.1 HAART knowledge

The type and level of HAART knowledge molds one's attitudes and perceptions of HAART. Since men's attitudes and perceptions towards HAART have been shown to influence PMTCT-Plus client's uptake of HAART, it is crucial that male knowledge on the topic be explored. FGD participants were asked to describe what they knew about HAART, if anything, and comment on their sources of this knowledge.

2.7.1.1 Lack of HAART knowledge among Males

A large portion of the respondents both from rural and urban areas indicated that they were aware of the existence of HAART, and believed that it was effective in treating people living with HIV/AIDS. Although most participants were cognizant of HAART, the level of knowledge seemed to be more basic than that of the women interviewed. Respondents from both urban and rural areas demonstrated similar levels of HAART knowledge, with most participants indicating that its existence and apparent efficacy was the extent of their HAART awareness. There were about one or two participant in each focus group that had never heard of HAART before. The following FGD excerpts exemplify the typical responses obtained regarding HAART knowledge.

"I just hear about them but there is nothing much that I know about the drugs- it has been something new you having called me to attend this study about these drugs". (R6-Urban FGD#1)

"For me what I know about those drugs is that they help people living with HIV/AIDS virus and prolong their lives. Instead of somebody dying within two years he/she dies after five or six years, this drug helps somebody not to die very soon. (R3- Rural FGD#2)

2.7.1.2 Sources of HAART knowledge

The sources of HAART knowledge cited by male participants were similar to those provided by the female interviews. As indicated in the female interviews, the radio was identified as most participants' main source of HAART information:

"[For] many years we've been hearing over the radios that when pregnant women go to the hospitals they are tested for HIV and those who are found positive are given those drugs free of charge". (R7- Urban FGD#2)

Another theme regarding HAART knowledge that reemerged in male FGDs was the lack of knowledge sharing by AIDS patients within the communities. Respondents from all of four focus groups indicated that HAART patients in their communities rarely shared their diagnosis or treatment details:

"People taking HAART are there [in the communities], but you can't know, no one can tell you [their HIV+ status]." (R8-Urban#1)

"I don't know of anyone on the drugs.-People fear to talk." (R1-Urban #2)

Considering that for most of these men, radio advertisements and rumors constitute the sole source of HAART information several HAART misconceptions, similar to those outlined by female participants exists.

2.7.1.3 Misconceptions

As in the female interviews, the misconception that HAART brings about weakness in its patients was raised. This common misconception was mentioned by multiple respondents in all four of the male interviews, as indicated in the following passages:

> *"I think that some women fear to take [HAART] because the drugs are very strong and they weaken some people who take them and others have decided to leave them."* (R1- Urban #1)

> *"[People] said that when you start on these drugs and then you stop you can even die and this is one of the reasons as to why people have feared to go and test to get the drugs."* (R5- Urban#2)

These misconceptions of the drug were cited as possible reasons hindering people to test for HIV/AIDS and take HAART. In addition to misconceptions regarding HAART use, several knowledge gaps were identified.

2.7.1.4 Knowledge gaps

In addition to the widely held misconceptions regarding HAART, significant gaps in knowledge were identified. Each focus group ended with a questioning period whereby participants were encouraged to voice any questions, comments or concerns they had on topic of low postpartum acceptance of HAART. These questioning sessions typically lasted between one and two hours. The length and content of these questions made it obvious that the respondents had many questions about both HIV/AIDS and HAART and exhibited a keen interest in learning more. The most common question raised was whether or not HAART cures AIDS.

> *"We hear that [HAART] reduces the virus in the body and you live a bit longer but what I don't know is whether it totally cures AIDS so I beg you to explain more and let us know the truth about these drugs."* (R1-Urban FGD #1)

> *" If I am 30 years old but the disease has eaten me up and I am only left with maybe two years to die, if I start taking those drugs, will I be cured?"* (R7-Rural FGD #1)

This particular knowledge gap was previously reported by female participants, suggesting that this aspect of HAART is largely unknown among the Kabarole population. The last quotation is indicative of another knowledge gap also exhibited in female interviews, regarding the optimal time to start HAART. This comment refers to the common practice of waiting until one is very ill before beginning HAART.

While most questions directed towards the research assistants were treatment related, questions surrounding HIV/AIDS were also voiced. The following quote concerns the utility of the condom and whether or not it plays a role in the treatment of HIV/AIDS:

"There is another question, we hear people telling us to use condoms, to use condoms, does a condom act as a medicine or is it just for prevention?"(R3-Rural#1)

Although this comment does not specifically address HAART, it does signal a lack of knowledge regarding HIV/AIDS treatment among these men. Despite lacking HAART awareness in some areas, participants from all four groups made it clear that they desired to be informed about the drug.

"Advise us about HAART. Some of us we don't know anything about these drugs, so teach us so we can know something." (R4- Urban FGD#2)

The strong desire to attain HAART knowledge was demonstrated not only through comments such as those above, but also the respondents' enthusiastic participation in the discussion. It became apparent that the FGD itself was seen by participants as HAART education or "sensitization". The observation was supported when, subsequent to the interview, respondents thanked the interviewer and principle investigator for teaching them about HAART. Many respondents made the point that unlike women, who are counseled in antenatal clinics, men are not presented with an opportunity to be taught about HIV/AIDS and HAART as women do.

"Women are sensitized when they go for antenatal care. Men should also be sensitized by all means so they can test." (R3-UrbanFGD #2)

In response to the lack of male counseling, participants recommended that HAART sensitization targeting men be carried out in villages to increase awareness:

The problem is poor sensitization. People don't know much about these drugs, radios are not enough. People should come and reach down from Local Council 1, from the villages some people even don't take time to listen to radio programs." (R3- FGD Urban #2)

Such comments as the one above convey these men's preference for an interactive approach to HAART education over existing methods of relaying HAART information through the media. Many of the participants communicated that this type of HAART sensitization would likely encourage men to go for HIV testing, as demonstrated by the excerpt below:

"Men should be given more attention, sensitize and show them the benefits of testing and accepting to live positively." (R2- Rural FGD #1)

2.7.1.4 Low HIV testing among men

Lack of male testing was frequently referred to by female respondents as contributing to non-disclosure or fear of disclosure to one's partner. To gain a male perspective on the topic of HIV testing, a considerable portion of each focus group discussion was dedicated to dialog surrounding male HIV testing. Respondents were asked to comment on the possible reasons for low testing in men, speculate how low testing among men affects women's decision to take HAART and provide suggestions on how male HIV testing uptake could be improved.

2.7.1.5 Reasons for low uptake of HIV testing among men

As previously mentioned, many respondents felt that a lack of HIV/AIDS and HAART knowledge among men may contribute to their low VCT uptake. Respondents expressed several other factors that may discourage men from testing. These include: The cost of testing, time and priority conflicts, worries associated with testing as well as a general reluctance to test for HIV.

Cost to clinic

A lack of finances was identified as a barrier to accessing HIV testing services. These echoes of the female interview findings, that identified economic restrictions, particularly transport costs, to limit clients' abilities to uptake the free HAART program. Transport costs to the clinics were also said to restrict men's ability to come to the clinic for testing.

"Some of us don't have transport and we hesitate going to far places for testing" (R6- FGD Rural#1)

Most HIV testing sites in Kabarole District provide free services to those coming to test. Apparently free testing is not universal throughout the district as some respondents mentioned a charge associated with testing, acting as an additional impediment to this service.

"Even there at the sub-county health unit they charge two thousand five hundred shilling per head. So if you are to go with your wife that's five thousand, which we don't have- that also makes us reluctant. We have other problems and requirements at home." (R8-Rural FGD #2)

The mention of economics and its role as an obstacle to testing was pervasive throughout the male focus group discussions. Men also commented that, being the primary breadwinner in the family, men are often too consumed working to support their families they have little time for testing. This sentiment is represented in the quotation below:

"For us [men] we are always busy looking for money to pay school fees, buying salt at home, we feel lazy to go for testing."(R4-FGD Rural#1)

This excerpt expresses a sentiment that was repeated by many other respondents, that being tested interferes with their ability to work and is often regarded as a nuisance rather than a priority. Participant five's following remark implies that an HIV+ diagnosis resulting from testing brings worries that can also interfere with one's ability to work.

"Men do a lot of hard work- working from morning until late in the evening , so they say when they test and maybe they are HIV+ they will have many worries

and they will not be able to work. That is why they don't test." (R5- Urban FGD #2)

The notion that an HIV positive result brings worries was frequently mentioned by respondents. The meaning of the term "worries" in this context was clarified by Ugandan team members. Team members explained that these comments convey a fear of learning one's HIV+ status, as this diagnosis forces those infected to confront the possibility of severe illness and imminent death. This fear prevents men from coming to test for HIV as portrayed in the following citation:

"Men are also infected but they fear. They say I'd rather die without knowing that [I'm HIV positive] because if I get to know I will die faster because of too many worries." R4- Urban FGD #1

Apart from the reasons provided above for non-testing by males, respondents also explained that unlike women, men are stubborn and less accepting of HIV testing.

"For me I think, as you have told us earlier, that the women are the ones who mostly go for testing and for us men, we are hard hearted. It is only women who can come and tell you that she has such and such a disease, and that is when I will get the encouragement to go and look for the treatment of the disease." (R2- FGD Rural #1)

Participant 2 expresses this position by explaining that men generally avoid hospital visits unless it is absolutely necessary.

"For us men we don't mind [going to the doctor] unless we are totally sick, we won't mind going to the hospital." R6- Rural FGD #2

Men's reluctance to test for HIV has been described to play a major role in women's decision to drop out of the free treatment program. Male respondents were asked to comment on solutions to improve HIV testing by men. Informants provided several suggestions, the most popular being the implementation of mass testing. The idea of mass testing emerged from all four focus groups. Many participants proposed that testing be carried out in a manner similar to immunization.

"I am saying making [HIV testing] general like it is with immunization so the government should set test dates meant for mass HIV testing". (R1- Urban FGD #2)

"Make testing as immunization so we know that such and such months of the year are meant for mass HIV testing and bring the exercise closer to people." (R2- Rural FGD #2)

In addition to carrying out mass HIV testing, participants above mentioned bringing the exercise closer to people thus eliminating the necessity for transport costs. This idea of increasing accessibility through decentralization of testing and treatment services was a popular solution provided by both men and women interviewed.

2.7.1.6 Fear of Serostatus disclosure

Being that non-disclosure among partners was raised as a concern by female respondents, several questions were asked surrounding this issue. Respondents were asked whether or not they would share a HIV positive diagnosis with a partner. This question yielded mixed responses, with the majority indicating that they would share their status with their partners. Surprisingly, there was a large number who indicated that they would withhold a positive diagnosis from their partners. A handful of men explained that if diagnosed positive, partner disclosure would be contingent on their partner's diagnosis. They explained that if their partner revealed a discordant diagnosis, they would be more likely to keep their positive status a secret.

"For me I was thinking that maybe I can go for testing first before the woman goes there and I test HIV+ and I fear to tell her and when she goes there afterwards and she tests HIV-, then for me I will fear to tell her."(R3- Rural FGD#1)

"I may inform her [of my HIV+ status], and I put all my trust in her but when she goes and tests and finds herself HIV-, as I trust her I may not tell her instead I will keep on using a condom." (R8- Rural FGD #2.)

Both respondents above communicate the act of disclosure to be reliant upon their partner's diagnosis. These comments implicitly assume that partners would be open about their tests results. This type of thinking may perpetuate secrecy between partners and compromise treatment uptake, as a considerable number of women interviewed had confessed to withholding their diagnosis from their partners.

Male informants were asked to provide their rationale for partner non-disclosure in the case they were found to be HIV+. The responses indicated that just as the women interviewed, many men fear blame and abandonment by their partners. Most men cited this fear as the primary motivation for partner non-disclosure. Participants from all FGDs, both urban and rural groups expressed this sentiment. The following comment illustrates this point.

*"I can't tell her, she will run away and leave me with the children" (*R4-Urban FGD #2)

The next quotation explains that some men fear blame and abandonment not only resulting from disclosure of an HIV+ status but by merely suggesting testing to his partner:

"If you the man brought the idea of testing, the woman will say that it means you are sick. She will start suspecting you to be HIV positive and she might even run away from you. (R5-Rural FGD#2)

In addition to fear of being abandoned, some men also expressed that sharing their HIV+ status could compromise their reputation and ability to find another woman in the event that he was deserted by his partner.

" The reason why we don't tell women is this one, when you tell the woman she will go out and tell all her friends and when she leaves your home, you fail to get another woman because she has destroyed your name and it is better to keep quiet instead of telling her."(R8- Rural FGD #1)

"I have first to reconsider the situation that when I tell her she may end up divorcing me if she is HIV-. What will I do then? Now will I go to look for somebody else who has the HI virus?"(R2- Rural FGD #1)

The data above demonstrates that the problem of low serostatus disclosure may be shared by both partners. Respondents were prompted to recommend ways in which to foster disclosure or circumvent partner non-disclosure. The most common solution offered was that couples should be counseled and tested together. Participants suggested that this would promote understanding and reduce non-disclosure among couples.

"For me I say there should be an understanding between the two and they both test and in case they are both sick of this disease they start the treatment." (R5- Urban FGD #2)

"I think with this issue of testing – it is better the two people be true to each other, both go and test and if they are to start the dose they both start that can benefit both of them."(R2- Urban FGD#1)

2.7.1.7 On PMTCT-Plus clients' Low uptake of HAART

To elucidate men's views on the issue of low HAART uptake by PMTCT-Plus clients, respondents were asked to speculate the possible reasons for the underutilization of free HAART services. The responses obtained suggested that participants were well aware of men's influence on their partners' decision to take HAART. The most popular conjecture was that women did not take HAART to conceal their HIV+ diagnosis from their partners. Fear of blame, violence, abandonment and lack of economic support were listed as possible motivations for this secretive behavior. These responses were consistent with female respondents' reasons for non-disclosure. Many participants mentioned fear of blame as a reason for non-disclosure leading to the rejection of treatment. This concept is outlined in the quotation below:

"The woman fears maybe because she still loves the husband and maybe they have children so she decides to keep quiet to avoid conflicts at home because she fears the man might say she is the one who brought the disease." (R4- Urban FGD #2)

The male interview data, as shown in the above excerpt acknowledges that women may avoid taking treatment for fear of being blamed for acquiring the disease. This fear was frequently mentioned by female respondents. Multiple comments made by male respondents suggested that this fear is not unfounded. A handful of participants felt that women are promiscuous and largely responsible for the spread of HIV/AIDS. The following quote justifies the act of blaming women for contracting the HIV on the supposition that women are generally promiscuous.

"Most men think it is women who bring the disease. These days you can hardly find a virgin girl very few men have married virgin girls." (R2- Urban FGD #2)

The following rural participant explains that more women than men are tested because they are promiscuous and more likely to become infected with the HI virus.

"Men don't involve themselves too much in sexual activities. But for women the reason why most of them go for testing is that they are too much involved in sexual activities." (R4- Rural FGD #1)

It is the above type of reasoning that instills in fear of blame among female patients, preventing some from disclosing their status among partners.

Some male FGD participants also identified fear of violence as a cause for secrecy and/or non-disclosure leading to low acceptance of HAART. Fear of violence as a barrier to disclosure and treatment acceptance was cited by several participants among the four focus groups.

"Some women are beaten by their husbands at times for no good reason if then he saw you swallowing drugs, he'd kill her."(R6 Urban FGD #2)

FGD participants also cited the possible loss of economic support as a motivation for non-disclosure among females. They explained that as many women depend on their partners for economic support, abandonment as a result of HIV+ status disclosure would eliminate this monetary resource on which they rely for survival. This may discourage some women to reveal their diagnosis to their partners.

"As you know in most homes it's the men who work so women fear that if their husbands got to know then they will leave them and they will have no one to buy the food or pay the school fees for their children." (R8- Urban FGD #2)

Another respondent said:

"She fears if the man comes to know about it, she can divorce her and you know people are poor, she will start suffering with no-one to help her. Poverty is the problem. If someone knows she can support herself without the man then she can start the drugs without even telling the husband."(R 1-383 Urban #2)

As demonstrated above, many of the men interviewed were aware that partner non-disclosure of HIV+ status may represent a barrier to accepting free HAART by PMTCT-Plus clients.

Fear of being known as HIV+

Another social factor that men indicated may inhibit women from disclosing their status or taking HAART is fear of being identified as an AIDS patient by community members. This is indicated in the following quotation:

"They fear that people will start to finger point at them that so and so is sick so they keep quiet." R9- Urban FGD #2

This motivation for low uptake of HAART was mentioned by only a few male FGD participants. Fear of being known as HIV+ was mentioned by PMTCT-Plus clients several times but was not identified as a prominent deterrent to taking HAART. Another participant's remark echoes some PMTCT-Plus clients' statements that women may fear being seen in the HIV/AIDS clinic or 'Yellow house' can alert others to patients' positive HIV statuses.

"People fear being identified because if they saw her at the clinic then people will start saying so and so family is all sick. " Respondent Urban #2

Social Support

As the presence of social support has been shown to improve HAART uptake, respondents were asked if they would support a partner who was found to be HIV+. All respondents' commented that support would likely improve HAART uptake and they would support their partners if they were found to be HIV positive. There were no participants who communicated otherwise. The means of support suggested by respondents included provision of transport costs, encouragement and reminding. Below are examples of these comments:

"I would always try and get for her transport when it is time for her to go back to the hospital for more drugs." (R4- Rural #2)

"I would motivate, encourage her and to always remind her when it is time for taking the drugs." (R1- Rural #2)

2.7.1.8. Health Care Decision Making

A common theme that surfaced from female interviews was women's reliance on their partners when making health care decisions. Most women explained that they first sought permission from partners before going to the clinic. This lack of health care decision autonomy on the part of females may inhibit HAART uptake in some clients, especially those who had not shared their diagnosis with their partners. To explore the process of Health Care Decision making within the home, inquiry into who is responsible for the health care seeking decisions was made. Many participants had difficulty understanding the meaning or purpose of this question. This may be attributed to unclear wording, although this is unlikely as questions had previously been pre-tested for clarity. Often this question had to be repeated or reworded so that participants were able to understand and answer this question. Some participants explained that decisions were made as a couple whereas others expressed that husbands/male partners were responsible for all decisions made in the home. There were relatively equal numbers of each response. The following respondent's comment indicates that the male family head is responsible for decisions made in his home.

"As the family head, you have responsibilities, so let this issue of starting HIV+ drugs if you are both positive be your responsibility too." (R9- Urban FGD #2)

This notion of the male as the family head was mentioned by several participants and was reinforced by motions of agreement from FGD members. From the discussion it seemed that the family head was typically the male, and was the dominant partner in the relationship, responsible for most household decisions. Respondent four in the second urban FGD share the sentiment that female partners are to assume the subservient role.

"The woman will always follow what the man has said and if she is a good wife she will not go against it." R4 Urban FGD #2

This statement demonstrates the expectation of submission and obedience by women among some men. From the female interview data, this attitude was shown to extend to health care decision making for some couples, with the women seeking permission to take HAART. Not all participants shared this view, as demonstrated by the following quote:

"[Deciding to take HAART] has to be an agreement between the husband and wife- with life no one has the right over the other's life. No permission. If she is found HIV+ and can get the drugs why then should she seek permission?" (R3 Rural FGD #2)

The section above provides insight into the role that men may play in the problem of HAART access and acceptance of HAART by PMTCT-Plus clients. Considering the major role that men play in women's decision to take HAART, men's view, knowledge and attitudes towards HIV/AIDS, HAART should be considered.

CHAPTER THREE: DISCUSSION

Treatment seeking behaviors such as accessing and accepting HAART can be described as spanning a continuum, from acknowledging risk to determining HIV status to accessing and continuing treatment (MShana et al, 2006). Patients experience an assortment of barriers at each phase along the continuum, an occurrence dubbed the "attrition cascade" by some authors (Stringer et al, 2005). This study identifies and explores the barriers facing PMTCT-Plus patients at the access and treatment maintenance stage.

The data extracted from this study provides insight into the context within which these women live. This perspective is essential in achieving a holistic understanding of the root causes that lead to low access and acceptance of HAART. Numerous factors were found to contribute to poor postpartum uptake of HAART which will be discussed below. A thorough comprehension of the factors facilitating poor uptake of HAART is instrumental in the development of recommendations to support, enhance and improve the existing program and uptake of HAART by PMTCT-Plus clients.

It is important to note that since the PMTCT-Plus program had only been newly established in 2003, at the time of the interview, participants had only been taking HAART for a few years up to a maximum of three years. The barriers identified in this study are therefore those experienced during the early years of treatment. Other barriers to access, such as treatment fatigue that have been mentioned in other studies did not emerge from this study, however may arise following a number of years on HAART by these patients. Other studies have found that adherence to HAART generally decreases as time goes on (Mills et al, 2006). It is therefore likely that Buhinga's PMTCT-Plus may experience more drop-outs over time. This is problematic, as the occurrence of non-acceptance and drop out of the PMTCT-Plus programme is presently unacceptably high.

The problem of low access of HAART services is not the only case of poor utilization services in the area. According to a 2001 estimate, (Uganda's Ministry of Health Abstract, 2001) the per capita utilization of out-patient services in

Kabarole District is 0.67, which is lower than the recommended 2-3 visits per capita. Evidently, service utilization is generally low. In Kabarole District, antenatal service utilization by women is 90% (Walter Kipp, personal communication) which is comparable to the national average of 92% (Ministry of Health, 2001). Although this number is high, many patients attend on average two to three visits, as opposed to the recommended ten, suggesting still that antenatal service access is low.

Economics

In resource poor settings, a lack of finances is a significant obstacle to accessing treatment, as has been shown by several studies conducted in sub-Saharan Africa. In Nabukera et al.'s study on the use of postpartum health services in rural Uganda, it was found that lack of money for transport was a key reason for failure to return for post-partum care visits (2006). Other studies conducted in Sub-Saharan Africa have demonstrated that funding shortages can contribute to poor HAART adherence (Hardon et al., 2006, Weiser et al., 2003). Hardon et al.'s (2006) study, a synthesis of findings from Botswana, Uganda and Tanzania described constraints to adhering to HAART among HIV patients. The two greatest barriers were related to financial constraints. These included the high cost transp[illegible]nd user fees as well as hunger resulting from failure to purchase the necessary supplementary diet. Throughout the course of this study, it became obvious that poverty was also overwhelming obstacle to obtaining and continuing HAART in Kabarole District.

Although HAART is provided to PMTCT-Plus clients free of charge, the logistical costs associated with retrieving and ingesting the drug is often unaffordable to PMTCT-Plus clients. These logistical costs included high transportation fees, the additional cost of purchased meals, spending the night in Fort Portal, missing work as well as purchasing the supplemental diet required.

Transportation Costs

High transportation costs emerged as the primary obstacle to taking HAART among all four groups of participants. It was identified as a barrier to enrolling for free HAART as well as continuing the drug. The requirement for recurrent monthly visits compounded this financial dilemma. Most participants interviewed account spending between 5,000 and 10,000. The amount spent on transportation represents a significant portion of a household's income, as the average monthly household expenditure in Uganda in 2000 was estimated to be 9,711 USh (Uganda Country Report, 2000).

PMTCT-Plus clients' area of residence and occupation seemed to be a strong determinant of clients' inability to cover transportation costs. The majority of respondents, particularly those not taking treatment, resided in remote rural areas where transportation costs were high. In contrast, it was found that a greater proportion of those participants currently taking HAART resided in urban areas within short walking distance of the hospital. Proximity to the clinic appears to be an important determinant of access to HAART. This finding is problematic, as the majority of Kabarole district's population resides in rural areas (Ugandan Population and Housing Census, 2002). According to the Ministry of Health's 2001 Statistical abstract, roughly 26.1% of Kabarole's residents reside within a 5km walking distance of health care facilities. This would explain the low access to services that many of the participants interviewed expressed. Most respondents, particularly those living in rural areas, were peasant farmers, the most prevalent occupation among Kabarole's citizens. A number of participants divulged that being a farmer gives rise to additional challenges when taking HAART, such as restricted access to cash and low income, insufficient to cover transportation costs.

This finding of transport costs as a barrier to accessing treatment is consistent with others who have conducted similar studies in Sub-Saharan Africa (MShana et al, 2006; Weidle et al, 2002; Weiser, 2003 and WHO/UNAIDS, 2006). In MShana et al.'s rural Tanzanian study, transportation costs were covered for a short period of time. During this interval, it was found that access and adherence to HAART had increased, indicative of the significance of transport costs as a barrier.

Despite being highly motivated to start and adhere to HAART, transport costs represent a formidable barrier preventing HAART patients from doing so. Not only do transport costs inhibit clients from beginning HAART, it also promotes low adherence which undermines the cost-effectiveness of the treatment by facilitating the development of resistance to first line drugs (WHO/UNAIDS, 2006). It is important that efforts are made to mitigate the problem of high transportation costs. Reducing or eliminating this barrier would likely increase HAART acceptance and adherence substantially.

Supplementary Food Costs

Although attaining and consuming the required supplementary foods was described by HAART patients and defaulters as a challenge to taking HAART, none of the participants interviewed cited this as the leading cause of their decision to default. Some respondents explained that if they were unable to acquire the recommended foods, they would continue with their regular diet, consisting primarily of starchy foods, the typical Ugandan staples such as matooke, posho and millet porridge. It seems surprising that many of these respondents who are peasant farmers would have difficulty obtaining nutritious foods such as vegetables and fruit. Participants explained that these foods were either not grown in their gardens, or were sold or traded for other necessities. Hunger or failure to obtain healthful foods was also found to pose a challenge to taking HAART in other studies (MShana et al, 2006; UN/WHO AIDS, 2004). Unlike this study however, they described failure to obtain supplementary foods as a challenge rather than a barrier to taking treatment.

Many respondents suggested that healthy foods be provided to HAART patients to alleviate the challenge of obtaining these nutritional supplements. A few respondents referred to the former GTZ-run PMTCT-Plus program that supplied clients with nutritious foods. The UN/WHO AIDS report (2004) "From Access to Adherence" also suggests that the provision of food-baskets to HAART patients, especially during the early phases of treatment would promote adherence. An initiative such as this would be costly and may be difficult to sustain long term without proper financial backing, however would alleviate one of the many challenges HAART patients face in taking their medication.

Other costs associated with clinic visits

Other costs associated with hospital visits were mentioned by respondents. These included the cost of purchasing meals while at the hospital and complaints regarding the cost of spending the night in Fort Portal. These additional costs are a direct consequence of the congestion and excessively long wait times at the clinic. In order for this additional cost to be mediated, the problem of long wait times would have to be addressed.

Another cost that was expected to emerge as a barrier was that of missing time at work and lost wages during their time at the hospital. There were however, only two respondents that indicated this to be a problem. Both of these women were working outside of the home, one as a secretary and the other a shoe kiosk owner. Overall, the issue of lost wages did not appear to be a substantial barrier to taking treatment, unlike the findings other adherence studies (UN/WHO AIDS, 2004). This may be a product of the farming lifestyle of most respondents. Many of the participants explained that leaving work was of no consequence, as they were not paid for their work.

The cost of leaving children behind to attend the clinic for appointments was also anticipated to surface as constraining treatment. Study data demonstrates that this was not considered a barrier by clients, who explained that their children were often cared for by family members or neighbors free of charge.

HEALTH CARE SERVICES

The quality of health care services delivery was found to be instrumental in cultivating patient satisfaction, motivation and promoting access and acceptance of HAART by PMTCT-Plus clients. The data collected revealed marked discrepancies in the quality of services received at the GTZ-run clinic in comparison to those received at the yellow house. Most clients expressed a considerably higher level of satisfaction with the services at the GTZ-run clinic compared to those received at the yellow house. The aspects of health care services delivery most frequently referenced as influencing their decision to take HAART included: distance to the facility, long waiting times and poor patient-provider interactions.

Distance to the Hospital

The previous section on high transport costs alludes to long distance as a treatment barrier. In addition to the high transportation costs incurred by clinic visits, most participants claimed that these distances were often too far to reach by foot. To mitigate this barrier of long distance and associated high transportation costs, decentralization of health care services as well as compensation for transport costs to and from the clinic could be implemented. These suggestions were also put forward by interview participants. Although compensation for transportation costs could be beneficial, this solution may be logistically impossible and unfeasible in the long term.

Long waiting times

Long waiting times at the YH was voiced as a major source of patient dissatisfaction and a barrier to treatment. Although the majority of respondents communicated dissatisfaction with lengthy wait times, only a handful cited long waiting times as a barrier to treatment. PMTCT-Plus clients in Kabarole are not alone in experiencing this problem. Excessive waiting times also emerged as an impediment to treatment adherence in other studies conducted in sub-Saharan Africa (MShana et al, 2006; Weiser et al,2003;WHO/UNAIDS, 2006).

To improve patient satisfaction and HAART adherence, an effort to reduce wait times should be made. Respondents described several factors such as multiple queues, patient favoritism by staff, disorganization of files and congestion to contribute to the long waiting times experienced by participants. Respondents indicated a clear need to increase the efficiency of services, such as improving general organization, client file management and altering time-consuming clinic procedures such as queuing in multiple lines for physician visits and drugs. Although some of these setbacks may be addressed, such as improving general organization, others may prove more difficult under the existing circumstance of extreme manpower shortages.

Patient Provider Interaction

Patients described instances of neglect, rude comments, shouting and patient favoritism by health care staff. This treatment of clients is unacceptable, as it results in poor patient provider- relationships, low patient satisfaction and discourages patients from taking HAART.

Ensuring favorable patient-provider interactions and patient satisfaction is essential, as it has been connected with increased levels of adherence among HAART patients (Bakken et al, 2000; Beach et al, 2006; Demmer, 2002). An important component of patient engagement is the communication methods used with patients. The Committee of Quality Health Care in America (2001) describes a communication style, patient-centeredness, as the standard for high interpersonal care. Patient centeredness which involves "understanding each patient as a unique human being" has been shown to bolster patient satisfaction (Brody DS et al., 1989). This is consistent with data collected from PMTCT-Plus patients who often associated a positive appraisal of the health staff and services with feeling welcomed and being known "as their patient". Conversely, poor staff communication styles such as the shouting and rude comments described by many participants discourage them from taking their treatment and should be purged from the HAART program. Improving communication styles is imperative in fostering positive patient-provider relationships and should become a priority in the Yellow house so that patient adherence to HAART can be increased.

The recurrent complaint of patient favoritism was also found to be detrimental to patients' motivation to take HAART. Staff favoritism should be reproached and a system should be put in place so that patients are served fairly. A numbering system whereby patients are tended to on a first come-first serve basis may be an adequate solution. To ensure desirable patient-provider interactions and improve patients' encounters with the health care staff, workshops, training sessions and supervision of established ethical guidelines focused on improving interpersonal patient-provider skills should be carried out.

Human Resources Constraints

Although the long wait times and poor patient-provider interactions are inexcusable, they signify a greater underlying issue: a lack of health care workers. Overworked and overburdened, health care workers may take their frustrations out on patients by shouting or communicating in a rude manner. In addition to this, congestion and time restrictions limit the amount of individual attention health care workers can bestow upon their clients, an act that can be interpreted by patients as neglect. These behaviors, congestion and inability to cater to all patients in one day as experienced in the HIV/AIDS clinic are indicative of the human resources crises that are currently plaguing the African sub-continent (Schneider et al., 2006).

Southern Africa is experiencing and inadequate supply of health care workers to meet rising health care demands. In fact, a lack of health care workers has been identified as the main system limitation to the scaling up of HIV treatment (Hongoro and McPake, 2003, Liese et al., 2003). Uganda also experiences this problem, as senior officials in Uganda stated a paucity of health care personnel as the key constraint to mobilizing responses to the country's health challenges (Human Resources in Africa. February, 2002).

Chen et al., (2005) explains that a feature of the human resources crisis is the demoralization and de-motivation of health care personnel in the system. In some cases, de-motivation and being subject to the pressures in the health care system has "in the worst cases turned full circle into a culture of abuse of patients" (Mackintosh et al., 2000). The recurring complaints of patient abuse by Buhinga Health staff may be a product of the stress incurred by challenging work environments such as those described above.

To begin to address the various problems such as long waiting times, congestion, neglect and poor patient-provider interaction that were raised by respondents, the complex issues related to of lack of health care personnel and resources needs to be considered.

HAART KNOWLEDGE and BELIEFS

A patient's knowledge and belief about HIV/AIDS and HAART is highly influential in one's decision to start and adhere to HAART. A basic understanding of HIV/AIDS, belief in HAART efficacy as well as knowledge of the consequences of non-adherence, such as treatment failure and viral resistance are said to lead to adherence in patients (Wenger et al, 1999; Weiss et al 2000). Study results indicate that for the most part, respondents possessed a basic understanding of HIV/AIDS and HAART. The majority of respondents indicated a belief in the efficacy of treatment and awareness of the drawbacks associated with non-adherence and defaulting.

The data found that there were no glaring differences in the formal education level between those taking HAART and those not taking the drug. This is contrary to conventional thinking, that acceptance and adherence may be a function of knowledge level, literacy and access to HIV/AIDS and HAART information. This study's findings suggest that financial constraints may be so overwhelming that it prevents access to HAART, regardless of patient's HAART knowledge and intentions to take the drug.

A marked disparity in the level of HAART knowledge was found to exist between respondents taking HAART compared to those who never enrolled for treatment. Lacking the counseling administered during enrolment, many patients felt their HAART knowledge level was suboptimal. Some patients suggested that they may have returned for enrollment if they held a greater awareness about the drug. Although eligible patients are not formally counseled regarding HAART prior to enrollment, they were provided with a pamphlet about HAART to take home and read. Interview data suggests that this may not be an effective method for HAART information dissemination among this group, as many PMTCT-Plus clients are illiterate or do not bring it home from fear of being exposed as HIV+ by family members or friends. Provision of a brief oral information session and increase in quality of the initial counseling to eligible PMTCT-Plus clients regarding HAART basics may be useful to improve patient HAART knowledge and HAART enrollment.

Several misconceptions regarding HAART surfaced over the course of the interview, the most popular being that HAART can be detrimental to the patient, making them weak and/or causing them to "die faster". Similar findings, that HAART was designed to kill PLWHA, arose from other studies in Uganda and was found to serve as a barrier to adherence (WHO/UNAIDS, 2006). This notion may arise from the initial side effects of dizziness, weakness and allergic reactions that some patients experience. Patients who delay treatment until advanced stages when they are less likely to recover, may give rise to and perpetuate the myth that HAART kills its patients (Kipp, personal communication). These misconceptions may deter patients from taking and adhering to HAART properly and efforts should be made to dispel these harmful fallacies. These misconceptions should be thoroughly investigated and addressed through education programs.

Knowledge gaps about HAART were also identified in the interview data, the most common being whether HAART cures HIV/AIDS. This question was raised by respondents taking and not taking treatment alike. To improve adherence to

HAART, it is crucial that respondents are aware that although HAART does not cure AIDS, it can increase the quality and longevity of the patient substantially if administered properly. Lack of knowledge regarding the outcome of HAART could potentially prevent patients from starting or adhering to HAART. This knowledge gap indicates a need to address the outcomes of HAART in counseling sessions and other HAART information sources.

Respondents described being exposed to HAART information through various avenues, the most common being radio, counseling and word of mouth. Radio shows focused on HIV/AIDS and HAART seemed to be a highly effective method of information dissemination, reaching an extensive audience. This is a reflection of the Ugandan government's efforts to increase HIV/AIDS knowledge across the country. The value of the radio as an effective tool for information dissemination was also acknowledged in studies from Botswana, Tanzania and Uganda (WHO/UNAIDS, 2006).

Participants rated their counseling sessions very positively, indicating it to be an excellent source of HAART information. Despite indicating a satisfaction with the counseling received, many patients requested additional sessions to expand and refresh their HAART knowledge. In contrast, HAART information transmitted via word of mouth in the villages was found to be a poor source of HAART information, perpetuating misconceptions and stigma. Increased efforts to improve HAART knowledge among village people should be made to dispel inaccurate beliefs that are responsible for generating stigma and discouraging patients from taking HAART.

SOCIAL ENVIRONMENT

HIV/AIDS Stigma

Stigma has long been associated with HIV/AIDS and its victims. Breeding hatred, denial, shame and secrecy, stigma is largely responsible for fueling the HIV/AIDS epidemic. Uganda has made the utmost effort to diminish stigma and cripple its effects (Kilian, 2002), making the country a leader of this effort on the African continent. Despite impressive advancements in the reduction HIV/AIDS stigma in Uganda, study data reveals that stigma persists in some communities, impeding access and acceptance of HAART by patients.

Most respondents reported occurrences of HIV/AIDS stigma within their communities. They claimed that PLWHA were regularly gossiped about, regarded as already being dead and unproductive members of society. Current efforts to roll out HAART could be instrumental in altering this insidious perception of those infected with the HI virus. Public insight into the increased quality and longevity of life experienced by HAART patients may inform people that HIV/AIDS is a manageable chronic disease, thus decreasing the stigma associated with the infection. The effect of HAART knowledge in reducing HIV/AIDS stigma was communicated by various interview participants. This reinforces the importance of educating the public about HIV/AIDS and HAART as a means to decrease HIV/AIDS discrimination.

Another discriminatory public sentiment expressed by respondents was that HAART patients take the drug to conceal their disease and intentionally infect others. The notion of deliberate spread of HIV by HAART patients validates Wawar et al.'s (2004) conjecture that "ART availability may result in behavioral dis-inhibition, increased risk behavior, and higher HIV incidence". Future research into the effects of HAART on risky sexual behaviors should be undertaken. Interventions to prevent risky behaviors in HAART patients should be implemented to decrease HIV/AIDS spread and decrease prejudice directed at HAART patients. Although most participants expressed that HIV/AIDS patients were viewed negatively by their communities, some community members were described to be accepting PLWHA. These encouraging statements signify the progress taking place in Uganda in terms of HIV/AIDS stigma reduction.

Stigma framed many aspects of the respondent's decisions and manifested itself as a treatment barrier in ways such as discouraging HIV testing among men, secretive behavior and partner non-disclosure. The study data shows that disclosure of HIV status was relatively high, with most clients disclosing their status to someone. Non-disclosure to respondents' partners seemed to be an issue of concern, however. Skogmar et al's study (2006) shows that HIV/AIDS stigma and discrimination are associated with partner non-disclosure. Partner non-disclosure was found to be one of the main impediments to taking treatment in this study, particularly among those who never began treatment and defaulters.

Partner Non-disclosure

Non-disclosure was asserted by most respondents, male and female alike, to be a substantial barrier to treatment. Non-disclosure to partners as an impediment to treatment has been recognized in other African studies, particularly pertaining to adherence (MShana et al. 2006; Nachega, J.B and Lehman, 2005; Olley et al,2004; WHO/UNAIDS 2006). Olley et al. (2004) and Nachega & Lehman (2005), found the rate of partner non-disclosure to be 22% and 38% respectively from their South African studies. This study's findings of non-disclosure as a barrier to treatment is therefore supported by others conducted in sub-Saharan Africa. The evidence underscores the severity of this problem and need for interventions to promote status disclosure among couples, such as focusing attention on the promotion of couples testing and counseling.

Similar to the findings from other studies, non-disclosure arose from fear of blame, violence, abandonment, divorce and loss of economic support (Gaillard et al, 2002; Maman et al, 2001; Medley et al, 2004). Study data demonstrated this fear to be a legitimate concern as a handful of respondents described such incidences occurring following disclosure to their partners.

Non-disclosure was also described to make HIV prevention strategies, such as wearing a condom challenging. This is supported by Simbayi et al.'s (2006) findings that indicate sexual transmission risk behaviors were reported more frequently among those who had not disclosed their HIV status to partners. This study also found that people who had withheld their status from partners were 28 times more likely to have sexual partners of unknown HIV status. This finding highlights the importance of male testing to facilitate partner disclosure. The issue of male testing will be discussed further in a following section.

Failure to practice protected sex has various implications. Several respondents described their inability to practice safe sex as a cause for defaulting; their reasoning being that practicing unsafe sex can decrease efficacy or render the drug ineffective. Large scale repercussions may ensue from this practice as well, including increased viral resistance to HAART, undermining HIV prevention and treatment efforts as well as catalyzing the spread of the HI virus. For these reasons, issues relating to partner non-disclosure should be addressed.

Social Support

Partner disclosure is important for establishing a treatment supporter and social network necessary to assist the patient in taking HAART properly. Selected treatment supporters were usually partners, family members (such as parents, siblings and children) and in a few cases, friends.

In accordance with Nachega et al.'s study (2006), the study results suggest that the process of taking and continuing HAART is eased with the presence of social support. The results also imply that taking and adhering to HAART is dependent on the fulfillment of basic financial, material and emotional needs. Financial and material needs such as transportation costs, lunch money and supplemental foods were identified by most participants as the type of support they are lacking that would improve their ability to take and adhere to HAART. Although emotional support was discussed as an important form of assistance, many patients claimed to be receiving this type of support and in addition required financial assistance. While most respondents stated that they possessed a treatment supporter who encouraged and reminded them to take HAART, they explained that these supporters often do not have the means to provide for them financially. This lack of financial and material resources was a recurring theme throughout this study.

Another recurring theme was the role socio-cultural factors related to women's gender roles and powerlessness.

Women and Powerlessness

A discussion regarding the barriers to taking HAART by HIV positive mothers would be incomplete without mention of Uganda's socio-culturally prescribed gender constructs and its role in women's decision to take and continue HAART. Gender roles and women's economic status seemed to play a role in some women's decision to take HAART.

Most participants described their duties and responsibilities to revolve around the home such as farming, cooking, cleaning and caring for their children and husbands. The gender role of women as caregivers was shown to represent a minor impediment to taking HAART, as only two respondents cited foregoing hospital visits to care for family members. This phenomenon was also observed in Turner et al.'s study (2000).

Women's duties as homemakers and caregivers also gave rise to economic dependence and lack of autonomy over health care decisions. Because homemaking work typically is unpaid, many women described they were reliant on their husbands for money, including treatment related costs. This economic dependency negated many women's autonomy over health care decisions, forcing them to seek permission and funds to visit the hospital. Several women were denied money for treatment costs by their husbands, impairing their ability to make hospital visits and adhere to treatment. In contrast, many women taking HAART cited financial independence and absence of a controlling partner as facilitating HAART uptake and adherence. This evidence suggests the importance of women's economic independence and autonomy in their abilities to take and continue HAART.

Among those respondents who described having to seek permission or funds to go to the hospital, very few specifically cited this as a barrier to taking HAART. Limited reference to lack of health care decision autonomy may indeed represent the absence of this factor as a barrier. This response may also be indicative of Uganda's socially accepted patriarchal rules governing women's behavior. If it is expected that men control finances and household decisions, seeking authorization would be considered a necessary practice rather than barrier to treatment. These socially accepted gender roles may also account for the confusion met by male respondents when asked to comment about the health care decision making process in their homes.

Female powerlessness and socio-cultural demands for female subservience gave rise to other treatment barriers. Fear of potential violence dictated many women's actions, often leading to serostatus non-disclosure. Violence against women is a common occurrence in sub-Saharan Africa, especially in intimate relationships (Ackermann and de Klerk, 2002), and is condoned in many African countries (Kiragu, 1996). Violent acts against women restrict women's behavior and represent a major barrier to treatment.

The challenge of practicing safe sex also arose from female powerlessness. Several respondents expressed a fear of negotiating condom use with their partners. Inability to suggest and practice safe sex led to non-disclosure and termination of HAART in some cases. Women's fear of suggesting condom use has been reported in other African studies, as it can be interpreted to imply misconduct on the part of the woman. Giffin and Lowndess (1999) comment that: "Women who attempt to introduce condoms into a relationship are often perceived by males as overly prepared for sex, not trusting their partner's fidelity, unfaithful themselves or even HIV infected". This statement was reinforced by comments made in interviews and FGD by male and female participants alike.

The examples above suggest that women's position in society is an important determinant of behavior, and needs to be considered when tailoring interventions to increase HAART uptake by women.

Stigma surrounding the Yellow House

The Yellow House is widely known as the HIV/AIDS treatment and care facility for Kabarole District. For this reason, any person seen entering the building is immediately identified as HIV/AIDS positive and are subject to the stigma projected towards those with the disease. The physical set up of this treatment facility denies its patients' their serostatus confidentiality, instilling discomfort in many patients and deterring patients from accessing these services in some cases. Provision of HIV/AIDS services alongside other health care services from within the main Buhinga building would be less conspicuous and therefore allow patients to remain anonymous, and avoid the stigma associated with HIV/AIDS patients. Respondents themselves provided this recommendation, often citing the GTZ clinic, that served its clients from a room in the out patients department as being the ideal set up. The viability of integrating HIV/AIDS services in with other health care services should be explored.

Patient Physical Health and Disease State

Participants' responses indicated that perceived health state plays an important role in one's decision to start HAART. Despite clinical indications that they should start HAART, many patients postpone treatment until the onset of severe symptoms. This deferment was often an attempt to conserve money that would otherwise be spent on transportation and other treatment-related costs. Two patients revealed that they were delaying treatment for fear of experiencing side effects that could impede their ability to work in their gardens to support their families. The rationales behind delaying treatment underscore the importance of economics as a barrier to treatment.

Multiple participants' statements suggest that being bedridden was the expected point of entry into the treatment program. There is an ongoing debate regarding the optimal point of HAART initiation in asymptomatic individuals, however there is statistical evidence that deferment of HAART to advanced stages (below

200 CD4 cells/mm^3) increases patients' risk of progression to AIDS and death (Merito and Pezzoti, 2006). Furthermore, studies reveal that HAART is most cost-effective if started when CD4 counts are higher than 200/mm3 (Merito and Pezzotti, 2006 and Badri et al., 2006). As it is both cost-effective and clinically beneficial to the patient to initiate HAART immediately when deemed eligible (CD4 count less than 200/mm3), patients should be discouraged from postponing HAART initiation. Clients should be educated about the optimal time to begin HAART in counseling sessions, so they can make a well informed decision regarding beginning or deferring treatment.

Adverse Reactions to HAART

Contrary to what was expected, side effects did not represent a major barrier to taking treatment. Only two respondents cited fear of anticipated side effects (weakness) as contributing to their decision to defer treatment. Of the defaulters, only two cited side effects as the cause. This is similar to findings in Botswana (Weiser et al., 2003), that found that side effects posed a minimal barrier to adherence. These findings are contrary to results from several developed countries' studies that cite side-effects as a major barrier to treatment adherence (Alfonso et al., 2006 and Chesney et al., 2000). Several reasons could possibly account for these differences. Being that the entry point for HAART is <200/mm^3, patients may feel so ill that the side effects experienced are attributed to be symptoms of the disease rather than outcomes of HAART. Another explanation is that counselors are effectively communicating anticipated side effects associated with the drug and patients, and in turn, patients are adhering to the drug as instructed (WHO/UNAIDS, 2006). This is a likely explanation, as many respondents expressed waiting out or consulting a physician upon experiencing adverse reactions.

Alcohol and substance abuse

Alcohol and/or substance abuse have been identified in previous studies as a barrier to adhering to HAART (WHO/UNAIDS, 2006). Alcohol or drug abuse was not mentioned as a barrier to treatment throughout the study. This may be a reflection of the cohort interviewed, who were recently pregnant mothers, a group less likely to drink compared to the general population. The low incidence of substance abuse reported as a barrier may also be a product of the social desirability bias. Since substance abuse is socially unfavorable, participants may not disclose their drinking/drug abuse as a reason for not taking HAART.

Another factor that did not emerge as a barrier to treatment was the use of traditional medicines in lieu of HAART. This is surprising, as traditional medicines for HAART were indicated to be available in the area. This finding may represent selection bias. Women who accept testing and HAART may be those who place faith in western medicine and are not apt to use traditional medicines for their ailments. Some respondents did, however, comment on using physician-prescribed septra, to prevent opportunistic infections while not on HAART.

Religion was mentioned by one respondent as a possible barrier to treatment for others, however, it did not surface as a barrier throughout the interviews with PMTCT-Plus clients.

Pill burden and treatment complexity have been described as barriers to treatment among HAART patients in other studies (WHO/UNAIDS, 2006; Mills et al., 2006). These were not found to represent a barrier to taking HAART in this study. This may be due to improvements in the simplicity of HAART, where triomune, the most common treatment constitutes only a single pill administered twice a day. Lack of complaints regarding treatment complexity or dosage schedule may also be indicative of the short period that these patients had been taking HAART. Patients may be tolerant of the complex and often inconvenient dosage schedule during the early years of treatment, a disposition that may wane over time.

Gender-Related Differences in Study Findings

The Male FGDs complemented and enhance the findings from PMTCT-Plus client interviews. Certain barriers to taking treatment were identified by PMTCT-Plus clients as being strongly influenced by male partners. To increase our understanding of these barriers, the male FGD focused on these aspects, which include: HIV testing by men, knowledge of HIV status, non-disclosure, relationship disruption and social support.

HAART knowledge

Men's HAART knowledge is influential in women's decision to access and accept HAART in several ways. Increased awareness of HIV/AIDS and HAART can decrease HIV/AIDS stigma, fostering understanding, prompting HIV testing and knowledge of ones' status, facilitating partner serostatus disclosure and establishing a treatment supporter.

The FGD results indicated that the majority of men had been exposed to HAART information and were aware of its efficacy in treating HAART patients. Although HAART knowledge in these men was considerably high, it was seemingly lower than that demonstrated by females. An explanation for this is that PMTCT-Plus clients are either counseled about HAART in antenatal clinics or are more likely seek HAART information once made aware of their status and eligibility for the treatment.

Men's perceptions of low access and acceptance of HAART by PMTCT-Plus Clients

The male FGD data revealed that most men possessed insight and a good understanding of the barriers to HAART faced by women. Men speculated that the greatest barrier to treatment was non-disclosure to a partner for fear of violence, blame and abandonment. Many respondents shared the view that both partners were responsible for withholding their HIV status. Simbayi et al., (2006) reported this mutual serostatus non-disclosure between couples, as observed in a Cape Town study, as "the practice of not asking and not telling". This behaviour, a product of HIV/AIDS stigma, undermines initiatives to increase HAART uptake as well as curb the HIV/AIDS epidemic (Simbayi et al., 2006). Non-disclosure among partners is a critical issue that needs to be addressed. As mentioned before, partner testing, couples counseling and one-on-one counseling specifically regarding partner notification may be useful in mediating this problem.

Interesting results surrounding perceptions of women emerged from the data. Many respondents described women as generally promiscuous and therefore the primary vectors of the disease. This attitude fuels stigma against women, justifying blame and is likely to instill fear of violence, abandonment and divorce in women. A considerable number of male participants admitted that they would consider abandoning their partner if she was found HIV positive.

Despite accounts of possible blame and abandonment cited by respondents, all participants acknowledged the importance of social support in taking HAART. All respondents indicated that if an understanding between couples was achieved, they would indeed support their partners emotionally and financially if possible. This attitude is promising as treatment support, especially from sexual partners increases the likelihood of adherence (Jean et al., 2006). These statements support those of female participants that for the most part, partners did their utmost to assist them with their treatment. Unfortunately, despite best intentions, often partners do not possess sufficient financial resources to provide the financial support necessary.

Male FGD reponses regarding decision making in the home varied. Some participants claimed the man had the final say, whereas others claimed it was a joint decision. This supported data from female interviews, in which participants described varying degrees of autonomy over their health care decisions.

Male Involvement in HIV/AIDS and HAART activities

A major theme emerging from male FGDs was the paucity of education campaigns and HIV/AIDS interventions aimed specifically at men. Men explained that unlike women, who are exposed to HIV/AIDS and HAART information through antenatal clinics, men are not presented with opportunities to be educated or tested for HIV. Men need to make a conscious effort to access services such as these. To increase awareness of men about HIV/AIDS and HAART as well as increase HIV testing, men suggested that education sessions and HIV/AIDS-related services be brought to the communities. A suggestion to increase HIV/AIDS knowledge among men included carrying out workshops and seminars tailored for men about HIV/AIDS and HAART in the communities. To increase the number of men tested some men recommended that HIV testing be mandatory, while a few participants suggested HIV tests be brought to people's homes. Nuwaha et al's 2005 study in rural Uganda suggests that door-to-door testing may be effective. Of those Ugandan residents approached in their homes, 111,697 (86%) accepted pretest counseling and 98% of these people accepted testing. The outcome of this study suggests that in-home testing may be a feasible means to increase HIV testing among men, as well as all Ugandan citizens.

Male-partner acceptance of HIV testing has been a challenge, as stated by many PMTCT-Plus clients, and reiterated by Dr. Ali Moses, a former Buhinga employee (personal communication). Low rates of male-partner testing following antenatal testing are common throughout sub-Saharan Africa (Cartoux et al., 1998). It is important to the success of treatment roll-out that male partners uptake testing and counseling services. This would likely mitigate problems surrounding disclosure, increase understanding, social support and preventative behaviors among partners. To increase HAART uptake, PMTCT-Plus clients are advised to encourage partners to test and attend counseling. Despite these efforts, as reported, women's requests for partner testing are often met with resistance. To increase HAART uptake by PMTCT-Plus clients, the issue of low partner testing, including the barriers to testing, need to be addressed.

Barriers to male testing explicated in FGDs included: testing fees and cost to the clinic, interference with work and worries associated with a positive diagnosis. Testing and treatment of PMTCT-Plus clients' family members are free at Buhinga. Despite this, the transportation costs to the clinic for HIV testing are still unaffordable to many people, a barrier that has been recurrent throughout this study. Another barrier to male HIV testing expressed by participants was that they were too busy with work to come to the clinic. This barrier speaks to the inaccessibility of HAART clinics to those in the workforce. Extending hospital hours into the evening, when most working men are free, may increase accessibility, encouraging them to test.

Although the incidence of HIV/AIDS infection among women outnumbers that of men and much attention is due to mitigate this problem, it is important that men are not excluded from HIV/AIDS efforts. Exclusive focus on testing women in antenatal clinics and preventing MTCT may create the public perception that HIV/AIDS primarily a women's issue. This attitude towards the epidemic could deter men from learning about HIV/AIDS, undermine testing, prevention and control behaviours among men. It is important that men remain on the forefront of the agenda when tailoring HIV/AIDS prevention and control initiatives.

Fear that testing and being found HIV+ "bring worries" was another barrier to testing, a fear that has been found to be a deterrent to testing elsewhere (Gebrekristos et al., 2005 and J.H Day et al., 2003). The apparent fear of HIV+ diagnosis may be indicative of the stigma surrounding the disease and the discrimination HIV/AIDS patients experience. Respondents expressed that being diagnosed with HIV/AIDS forces patients to face the possibility of imminent death. Ngatia et al. (2000) comments that education sources portraying HIV/AIDS as a killer may promote stigma surround the disease that leads to these types of thoughts. Furthermore, a lack of knowledge regarding the availability of effective treatments of the disease may cultivate this intense fear of HIV/AIDS (Day et al., 2003). Needless to say, HIV/AIDS stigma and lack of HIV/AIDS and HAART knowledge is a strong deterrent to accepting both testing and treatment. Interventions focusing on these issues are necessary to increasing their uptake by men.

CHAPTER FOUR: CONCLUSIONS

The provision of free HAART to PMTCT-Plus clients and their families is crucial to the success of HAART roll out in Uganda. As elicited in this study, this initiative is faced with tremendous challenges and barriers that could potentially sabotage this effort. These barriers to treatment need to be addressed to increase access and acceptance of these life-saving drugs by HAART patients.

Economic factors represented the greatest barrier to treatment among all PMTCT-Plus clients. Although HAART treatment itself is free, the associated treatment costs such as those incurred by transportation, supplemental foods, purchased meals at the clinic and overnight stay in Fort Portal impeded patients from accessing treatment. These costs have been described as the culprit undermining patients' adherence in other sub-Saharan African studies as well (MShana et al., 2004 and WHO/UNAIDS, 2006). Furthermore, economic dependence on male partners was found to negate many women's autonomy over treatment decisions, acting as an additional barrier to treatment. Economic barriers are anticipated to persist as a significant barrier to taking HAART and efforts should be focused on reducing or eliminating these costs to improve uptake.

In this study, Health care service factors were also found to negatively affect patient satisfaction and to a lesser degree treatment seeking behavior, especially among defaulters. Patients reported a much higher degree of satisfaction with the GTZ staff and services compared to those at the MOH/JCRC run clinic. Long wait times, clinic congestion, patient neglect, and poor patient-provider interactions cultivated dissatisfaction among the majority of PMTCT-Plus clients, acting as a treatment barrier to some clients. Although a number of these problems can be immediately addressed, other problems, such as those stemming from lack of health care personnel, may require long term commitment, governmental and financial support. Nevertheless, interventions to improve these services need to be put into place to promote patient satisfaction and adherence.

Stigma framed the majority of women's treatment decisions and not surprisingly, represented a significant treatment obstacle. Despite Uganda's considerable success in increasing HIV/AIDS knowledge and combating stigma, study data shows that HIV/AIDS stigma still lurks within some communities, impeding HAART access and adherence. In this study HIV/AIDS stigma was found to give rise to discrimination of HAART patients by community and family members, partner non-disclosure, secretive behaviors and refusal/low acceptance of VCT services by PMTCT-Plus clients' partners. The many faces of HIV/AIDS stigma persists to impair both treatment and HIV prevention efforts, thus fueling the epidemic. Tackling this barrier demands an abundance of time, effort and money, however is necessary to curb the spread of the HI virus and bolster HAART uptake.

Knowledge of HAART among most PMTCT-Plus patients was found to be sufficient to take and adhere to HAART. Those who had attended enrollment counseling sessions exhibited a better understanding of the drug, facilitating its acceptance. Counseling sessions at the hospital and radio advertisements were found to be the most effective methods of HAART information, suggesting that these media should continue to be used as HAART information channels. Community dialog surrounding HAART was another major source of HAART knowledge, however was found unreliable in some instances, as it was stated to propagate misconceptions surrounding the drug. These misconceptions, in addition to knowledge gaps acted as a barrier to treatment for some respondents, particularly those who had not been counseled in enrolment sessions. This signifies a need to provide basic HAART information (in person, rather than on paper) to patients prior to enrolment sessions. The study findings stress the importance of disseminating accurate HAART knowledge among the public and identifies a need to increase HAART knowledge in communities and among PMTCT-Plus clients to promote HAART uptake.

Patient factors such as physical health and disease state were found to influence respondents' treatment-seeking decisions. Many clients claimed that despite being clinically eligible for treatment, they felt relatively healthy and therefore saw no need to initiate treatment. This was found to be an effort to avoid treatment expenses in some cases. It is important that patients are informed that prolonged deferment of treatment can be detrimental to one's health, impairing chances of recovery.

Interview data demonstrates that men seemed to be cognizant of many of the factors influencing low uptake of HAART among PMTCT-Plus clients. The male FGDs underscore the importance of male involvement in HIV/AIDS and HAART educational campaigns, testing and treatment initiatives. Particular attention should be paid to decreasing stigma surround HIV/AIDS and testing, as well as increasing accessibility of testing services to men. Improving the number tested among men may facilitate HIV disclosure and in turn social support between couples, including PMTCT-Plus Clients.

This study has identified and elucidated the barriers to accessing and accepting HAART experienced by Kabarole district's PMTCT-Plus clients. This study's findings are novel, in that very few, if any studies focus on HAART uptake within the context of the PMTCT-Plus programme. Unlike other studies that focus on barriers to adherence, this study also addressed the barriers to beginning HAART. The results reveal many similarities between the barriers facing women when starting and adhering to treatment, and stress the importance of mitigating economic and partner disclosure barriers to improve recruitment on the drug. The study findings also stress the importance of effective counseling to those who are found to be eligible for HAART treatment. Several results completely distinct from other studies also emerged, for example the absence of adverse reactions to HAART and alcohol and substance abuse as an adherence barrier.

Based on study findings, numerous recommendations, many put forward by participants themselves, have been made to improve the existing PMTCT-Plus services, HAART uptake and survival of PMTCT-Plus clients in Kabarole District.

4.1 Recommendations and Future Studies:

This study has identified a variety of barriers to treatment including those stemming from economic factors, social environmental factors, lack of HAART knowledge and beliefs, suboptimal health care services and patient factors. This qualitative, exploratory study has set the groundwork for future large scale quantitative studies into the barriers of treatment. This study focused on the cohort of PMTCT-Plus clients from 2003- 2006. An interesting follow up study would look into the barriers to accessing and adhering to HAART a few years down the road, to try to identify any new barriers to accessing treatment emerging in the long term maintenance phase.

A number of schemes may be useful in alleviating these problems. Several recommendations for increasing HAART adherence presented in "From Access to Adherence" (WHO/UNAIDS, 2006) are applicable to Kabarole's setting and have been incorporated into the recommendations provided below:

Recommendations to mitigate Economic Barriers:

Decentralization of Services- A popular recommendation put forward by several participants was the decentralization of services. Extending HIV testing and HAART services by opening peripheral health centers in rural areas would decrease the distance patients are required to travel, thus negating expensive transport fees that act as a major impediment. To complement this, the creation of referral services would ensure that patients are treated in facilities closest to their homes. This would serve to decrease both transport costs and waiting times (WHO/UNAIDS, 2006). Future research could address the feasibility and efficacy of HIV/AIDS-related service delivery through peripheral centers.

Home-based care is another form of decentralized services that could take place. This entails provision of medication and counseling services in the home and applies primarily to those patients in advanced stages who are unable to come to the clinic to retrieve medical attention or the HAART they require (WHO/UNAIDS, 2006).

Decrease frequency of hospital visits: Several respondents suggested decreasing the required frequency of hospital visits, especially during the maintenance phase of HAART therapy. This could cut down on transportation costs and promote treatment adherence among HAART clients. Conversely, decreasing required hospital visits and associated monitoring by physicians could allow poor adherence to go undetected, thus promoting non-adherence. Future studies could investigate the possibility of decreasing the frequency of required clinic visits for refills and its effect on treatment adherence (Jaffar et al., 2005).

Health Care Services Recommendations:

Improve provider-patient interaction: A number of improvements in the delivery of health care services could be made, particularly regarding provider-patient interaction. There is evidently a clear shortage of health care staff. An increase in the number of staff may mitigate problems of congestion and long waiting times in the clinic. Study data also suggests that improvements in patient-provider interactions are desperately needed. Staff should be trained on methods of positive communication with patients and encouraged to do so. Monitoring of provider-patient communication should be in place to ensure positive patient-staff interaction is occurring. Improving interactions between patients and staff should enhance patient satisfaction and encourage clients to take HAART. To further improve patient satisfaction, action should be taken to eliminate the patient favoritism that has been reported in the clinic. Patients should be served on a first-come-first-serve basis or follow the appointment guidelines previously set by physicians. As poor patient-provider interaction could stem from challenging work environments, a study into staff job satisfaction, burden, workload and suggested improvements may be useful to identify problems and improve service delivery.

Improve Follow-up of patients: Increased efforts to contact patients who are lost-to-follow-up are needed to promote adherence and decrease drop out rates from the HAART programme. Contacting patients lost-to-follow-up would ensure that patient files are kept up to date and barriers and problems with HAART can be identified and addressed.

Improved Organization within the clinic: Organizational improvements at the Buhinga HIV/AIDS clinic could increase efficiency of services. Efforts to improve the organization of patient files needs to be made to eliminate the problem of lost or missing files, thus increasing efficiency and decreasing waiting times and patient frustration.

Improvement of clinic procedures: Wait times could also be mitigated by improving procedures in the clinic. The current procedures require that patients first visit their physician before lining up to pick up their HAART dosage. This practice contributes to the congestion and long waiting times in the clinic. Shifting the dispensing responsibilities from physicians to clinical officers and nurses, especially among long term patients may decrease the burden on physicians, clinic congestion and waiting times.

Integration of HIV/AIDS services into Buhinga facility: As the yellow house provides exclusively HIV/AIDS services, any patient entering the building is immediately identified as being infected with the disease. Providing HIV/AIDS services within the main Buhinga building as opposed to a separate facility such as the Yellow House would be more discreet, decreasing the stigma placed on AIDS patients. The feasibility of integrating HIV/AIDS services into the main building should be explored.

Decrease HIV/AIDS Stigma:

Increase community sensitization: Increased efforts to improve community sensitization regarding HIV/AIDS and HAART may be needed to decrease

HIV/AIDS and HAART discrimination. Promoting Information, Education and Communication (IEC) via several media such as the radio, community seminars and community workshops could be highly beneficial.

Encourage Couples Testing and Counseling: Increased efforts to support and enhance existing initiatives promoting couples testing and counseling is needed. Couples testing and counseling are important in avoiding partner non-disclosure and improving the availability of support mechanisms. In addition to couples counseling and testing, counseling content should incorporate issues surrounding partner disclosure and the negotiation of safe sex with one's partner.

Promote Empowerment of Women

As many issues of female empowerment are deeply embedded in the society's values, a great amount of effort and time will be needed to improve female empowerment. Short term solutions to address this problem may be to incorporate dialog surrounding empowerment during enrolment counseling sessions, such as how to negotiate protected sex, persuade partners into testing and how to handle domestic violence and be provided with support programs for these women in the case of adverse outcomes of taking HAART.

Increase HIV AIDS and HAART Awareness:

Implement improved HAART counseling prior to enrollment: In addition to the HAART information pamphlet, PMTCT-Plus clients should be counseled about HAART, including the benefits of taking HAART and the optimal time to start HAART. This would increase basic HAART knowledge among clients so that an informed decision regarding enrolling in or delaying treatment initiation can be made. The misconception that HAART makes its patients weak or facilitates death should also be corrected during these sessions.

Address HAART misconceptions and knowledge gaps: HAART misconceptions and knowledge gaps should be addressed through various HAART channels, including counseling sessions. Enrollment counseling sessions should address the knowledge gaps and misconceptions identified in this study, such as the end result of HAART, the optimal starting point for HAART, risks of deferring treatment initiation and the option of childbearing.

Increase HIV/AIDS and HAART knowledge among men: Improving HIV/AIDS and HAART education, primarily among men is essential in evoking testing behavior and awareness among men, thus promoting understanding and support of PMTCT-Plus clients. The implementation of HIV/AIDS workshops for men may be an effective approach.

Promote HAART Adherence:

Train additional adherence counselors: Additional adherence counselors should be recruited and trained so that quality adherence counseling can be delivered. This may promote adherence among PMTCT-Plus clients, reduce the burden on nurses that double as counselors and in turn, decrease congestion and waiting times in the clinic (WHO/UNAIDS, 2006).

Increase Male Testing:

Improve Accessibility of HIV testing among men: Accessibility to HIV testing could be improved by extending clinic hours into the night to accommodate working men. By extending clinic hours, men would not be missing work to come to the clinic to be tested for HIV.

Decentralization of HIV Testing Centers: HIV testing centers could be brought to rural areas, to decrease distances and transport costs associated with being tested. If it is not feasible to permanently open testing centers in villages, temporary testing sites could be set up multiple times during the year, and residents encouraged to test during these specific times.

Above are several suggested recommendations to increase the uptake of free HAART by PMTCT-Plus clients, based on the findings from this study.

4.2 Information Dissemination Activities:

Dissemination of study information commenced following completion of data collection. In December 2006, a presentation of preliminary study findings and recommendations was made at the Community Based ARV Project Office in Fort Portal. Those attending included: The District Health Officer, CB-ARV Staff, select faculty members and students of Makarere University's Institute Public Health, relevant health care professionals and research assistants.

In January 2007, upon return to Canada, the Canadian investigator wrote a newspaper article on study findings and field research experiences for the Argosy, the student newspaper for Mount Allison University in Sackville, New Brunswick. She was also interviewed for an additional newspaper article based on study findings and field research experiences for the Truro Daily Newspaper in Nova Scotia. This article was published in February, 2007.

Presentations of Research Methods and Preliminary findings were undertaken at the University of Alberta in Edmonton in March and April of 2007. These included presentations at the School of Public Health's Student Seminar Series, as well as Global Health Rounds for the Faculty of Medicine.

Future Dissemination Activities will include: Study Findings and Recommendation Report for Buhinga hospital, Published articles, as well as possible further presentations and conference attendance.

References

Ackermann, L., de Klerk, GW (2002). Social Factors that Make South African Women Vulnerable to HIV Infection. *Health Care for Women International* 23, 163-172.

Alfonso V., Bermbach N., Geller J. & Montaner, J. (2006). Individual Variability in Barriers Affecting People's Decision to Take HAART: A Qualitative Study Identifying Barriers to Being on HAART. *AIDS PATIENT CARE and STDs,* 20(12), 848-857.

Badri M., Cleary S., Maartens G., Pitt J., Bekker LG., Orrell C.& Wood R.(2006). When to initiate highly active antiretroviral therapy in sub-Saharan Africa? A South African cost-effectiveness study. *Antiviral Therapy,* 11(1), 63-72.

Bakken S, Holzemer WI. & Brown MA, et al (2006). Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care STDs*, 14:189-197.

Beach MJ., Jeanne Keruly, CNRP et al (2006). Is the Quality of Patient-Provider Relationship Associated with Better Adherence and Health Outcomes for Patients with HIV? *Journal of Internal Medicine,* 21(6):661-665.

Benatar SJ, (2002). Reflections and recommendations of research in developing countries. *Social Science and Medicine,* 54(7):1131-1141.

Boyatzis RE (1998). Transforming Qualitative Information: Thematic Analysis and Code Development. (pp. 31). Thousand Oaks: Sage Publications Ltd.

Britten N (1995). Qualitative Research: Qualitative Interviews in medical research. *BMJ* 311:251-253, 22 July.

Brody DS, Miller SM, Lerman CE et al (1989) Patient perception of involvement in medical care: relationship to illness attitudes and outcomes. *J Gen Intern Med,* 4:506-11

Chen L, Hanvoravongchai (2005). HIV/AIDS and human resources [Editorial]. Bulletin of World Health Organization. 4: 243-244.

Cartoux M et al. (1998). Acceptability of voluntary counseling and testing (VCT) and interventions to reduce mother-to-child transmission of HIV. Presented at the 12th World AIDS Conference, Geneva, Abstract no. 23310.

Chesney MA (2000). Factors affecting adherence to antiretroviral therapy. *Clinical Infectious Diseases*, 20(Suppl 2): S171-6.

Committee on Quality Health Care in America (2001). Crossing Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press.

de Paoli M.M., Manongi R, Klepp K.I. (2004).Factors influencing acceptability of voluntary counseling and HIV testing among pregnant women in Northern Tanzania. *AIDS Care*, 16(4): 411-425.

Demmer C. (2003). Relationship with health care provider and adherence to HIV medications. *Psychol Rep*, 93:494-496

Narasimhan V., Brown., Pablos-Mendez, A., et al (2004). Responding to the global human resources crisis . *Lancet,* 364(9428):1469-1472.

Evans RG, Stoddart GL. Producing health, consuming health care (1990). *Soc Sci Med,* 31(12):1347-63.

Egger M., May M., Chene G., et al (2002). Prognosis of HIV-1-infected patients starting highly active antiretroviral therapy: a collaborative analysis of prospective studies. *Lancet*; 360: 119-129.

Ekouevi DK., Leroy V., Viho A., BequetL., Horo A., Rouet F., Sakarovitch C., Welffens-Ekra C. & Dabis F. (2004). Acceptability and uptake of a package to prevent mother-to-child transmission using rapid HIV testing in Abidjan, Cote d'Ivoire. *AIDS*,18(4):697-700

Fehr J.S., Nicca D., Sendi P., et al. (2005). Starting or changing therapy- A prospective study exploring antiretroviral decision-making. *Infection*; 33: 249-256.

Gaillard P., Melis R., Mwanyumba F., Claeys P., Muigai E., Mandaliya K., Bwayo J., Temmerman M. (2002). Vulnerability of women in an African setting: lessons for mother-to-child HIV transmission prevention programmes. *AIDS*, (16)6: 937-939.

Gebrekristos H., Mlisana K. and Karim QA. (2005). Patient's readiness to start highly active antiretroviral treatment for HIV. *BMJ*, 331:772-775.

Gill, C.J., Hamer D.H., Simon J.L., Thea D.M. And Lora L. Sabin (2005). No room for complacency about adherence to antiretroviral therapy in sub-Saharan Africa. [Opinion]. *AIDS,* 19: 1243-1249.

Glanz, K, Rimer, B.K. & Lewis, F.M (2002). Health Behaviour and Health Education. *Theory, Research and Practice.* San Fransisco: Wiley & Sons.

Gundel Harms, Angelika Mayer and Heiko Karcher (2003). PMTCT Prevention of mother to child transmission in Kenya, Tanzania and Uganda. Deutsche Gesselschaft fuer Technische Zusammernarbeit (GTZ) GmbH, Germany.

Rothe, JP. (2000). Undertaking Qualitative Research, University of Alberta Press.

Harries AD, Nyangulu DS, Hargreaves NJ, et al (2001). Preventing antiretroviral anarchy in sub-Saharan Africa. *Lancet,* 358:410-414.

Hogg RS., Heath KV., Yip B., Craib KJ., et al.(1998). Improved survival among HIV-infected individuals following initiation of antiretroviral therapy. *JAMA* 1998, 279: 450-454.

Human Resources in Africa. Workshop sponsored by AFRO and World Bank, Addis Ababa, February 2002.

Hongoro C. and McPake B., (2003). Human resources in health: putting the right agenda back to front [Editorial], *Tropical Medicine and International Health*, 8:965-966.

Im Eun, Page R., Lin LC., Tsai HM. and CY Cheng. (2004). Rigor in cross-cultural nursing research. *International Journal of Nursing Studies*, 41(8): 891-899.

Kilian A (2002). HIV/AIDS Control in Kabarole District, Uganda. Deutsche Gessellschaft fuer Technische Zusammenarbeit (GTZ) GmbH, Germany.

Dr. Walter Kipp, personal communication.

Kitzinger, J (1995). Qualitative Research: Introducing focus groups. *BMJ*, 311: 299-302 (10 March)

Kiragu Jane (1996). Policy Profile, HIV Prevention and Women's Rights: Working for One Means Working for Both. *AIDS captions* 2(3) (online) Available at:

http:// www.fhi.org/en/aids/aidscap/aidspubs/serial/captions/v2-3/cp2313.html

Liese B., Blanchet N., & Dussault G.(2003). The Human Resource Crisis in Health Services in Sub-Saharan Africa. Background paper, World Bank, Washington DC.

Lincoln, Y.S., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Mackintosh M. and Tibandebage P. (2000). Sustainable redistribution with health care markets? Rethinking regulatory intervention in the Tanzanian context. Discussion Papers in Economics No. 23, Open University, Milton Keynes.

Magnhild E., Myhre M., Lindback, et al.(2006). Social consequences of HIV-positive women's participation in prevention of mother-to-child transmission programmes. *Patient Education and Counseling*, 60(2):146-151.

Manzi M., Zachariah R., Teck R., et al(2005). High acceptability of voluntary counseling and HIV-testing but unacceptable loss to follow up in a prevention of mother-to-child HIV transmission programme in rural Malawi: scaling-up requires a different way of acting. *Tropical Medicine & International Health*, 10(12):1242-1250.

Maman S., Mbwambo J., Hogan N.M., et al. (2001). Women's barriers to HIV-1 testing and disclosure: challenges for HIV-1 voluntary counseling and testing. *AIDS CARE*; 13(5): 595-603.

Marshall, Marshall, P.A. (2001). The relevance of culture for informed consent in US funded international health research. Consultation Report for the President's National Bioethics Advisory Commission Volume 11 Ethical and Policy issues in international research: Clinical trials in developing countries. US National Bioethics Advisory Commission.

Medley A., Garcia-Moreno C., McGill S. & Maman S.(2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization*, 82: 299-307.

Meleis, A.I. (1999). Culturally competent scholarship: substance and rigor. Advances in Nursing Science. 19(2): 1-16.

Merito M., Pezzoti P. and the ICONA Study Group (2006). Comparing cost and effectiveness of different starting points for highly active antiretroviral therapy in HIV-positive patients. Evidence from the ICONA cohort. *The European Journal of Health Economic,* 7(1): 30-6, 2006 Mar.

Mills, E.J., Nachega J.B., Bangsberg D.R., Singh., Rachlis B., Wu P. et al.(2006). Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med,* 3(11):e438.

Ministry of Health (June, 2003). Antiretroviral Treatment Policy Draft. Republic of Uganda.

Ministry of Health Statistical Abstract (2001). Retrieved on September 12, 2007 at http://www.health.go.ug.docs/abstract.pdf.

Morse JM.& Field PA. Qualitative Research Methods Health Professionals (2nd Edition). SAGE Publications Ltd, 1995; 2-3.

MShana G.H. et al, (2006). Barriers to Accessing Antiretroviral Therapy in Kisesa Tanzania: A Qualitative Study of Early Rural Referrals to the National Program. *AIDS PATIENT CARE and STDs*, 20(9): 649- 657.

Nabukera S.K., Witte K., Muchunguzi C. et al. (2006) Use of Postpartum Health Services in Rural Uganda: knowledge, attitudes and barriers. *Journal of Community Health,* 31(2): 84-93

Nachega, J.B., & Lehman, D.A. (2005). HIV/AIDS and antiretroviral treatment knowledge, attitudes, beliefs and practices in HIV-infected adults in Soweto, South Africa. *J Acquir Immune Defic Syndr* 1, 38(2): 196-201.

National Antiretroviral Treatment and Care Guidelines for Adults and Children (2003). Ugandan Ministry of Health.

Nuwaha F., Muganzi E., Kasasa S., Achom M. et al., District-wide, door-to-door, home-based HIV voluntary counseling and testing in rural Uganda. Abstract XVI International AIDS Conference, Toronto Canada. 13-18th August, 2006.

Olley, B.O. & Seedat, S. (2004). Self-disclosure of HIV serostatus in recently diagnosed patients with HIV in South Africa. *Afr J Reprod Health,* 8(2): 71-76

Painter T.M, Diaby K.L., Matia D.M., et al.(2004). Women's reasons for not participating in follow up visits before starting short course antiretroviral prophylaxis for prevention of mother to child transmission of HIV: qualitative interview study. *BMJ*,329(7465):543.

Polit, D.F. & Beck, C.T. (2004). Nursing research: Principles and methods (7th ed.). Philadelphia: Lippincott, Williams & Wilkins.

Popp D, Fisher JD (2002). First do no harm: a call for emphasizing adherence and the developing world. *AIDS.* 16:676-678.

Rothe, JP (2000). Undertaking Qualitative Research, University of Alberta Press.

Rosenstock, I. M. (1966). Why people use health services. *Milbank Memorial Fund Quarterly*, 44, 94-124.

Schneider H., Blaauw B., Gilson B., Chabikuli N & Goudge J. (2006). Health Systems and Access to Antiretroviral Drugs for HIV in Southern Africa: Service Delivery and Human Resources Challenges. *Reproductive Health Matters*, 14(27):12-23.

Skogmar S., Shakely D., Lans M., et al (2006). Effect of antiretroviral treatment on disclosure of HIV-serostatus in Johannesburg, South Africa. *AIDS Care*, 18(7):725-730.

Stringer J.S., Sinkala M., Maclean C.C., et al (2005). Effectiveness of a city wide program to prevent mother to child HIV transmission in Lusaka Zambia. *AIDS*, 365:354-356

Taha T.E.T., Miotti P., Liomba G., et al (1996). Maternal death and child survival in Africa. *AIDS*, 10:111-112.

Turner B., Newschaffer C., Zhang D., et al.(2000). Antiretroviral Use and Pharmacy-Based Measurement of Adherence in Postpartum HIV-Infected Women. *Lippincott Williams & Wilkins*, 38(9): 911-925.

Uganda Country Report, 2000 Economic Commission for Africa. Retrieved on September 11th, 2007 from www.unecaresources/Major-ECA-websites/icdp/fourth/Uganda/htm

Wawar M.J., Serwadda D., Gray R.H., Berkely S., Sewankambo N.K., Musgrave S.D., Musagara M., Stallings Y.R., Konde-Lule J.K (1994). Incidence of HIV infection in a rural region of Uganda. *BMJ*, 308:171-173.

Weiser S., Wolfe W., Bangsberg D., Thior I., Gilbert P., et al. (2003). Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. Journal of Acquired Immune Deficiency Syndromes, 34:281-288.

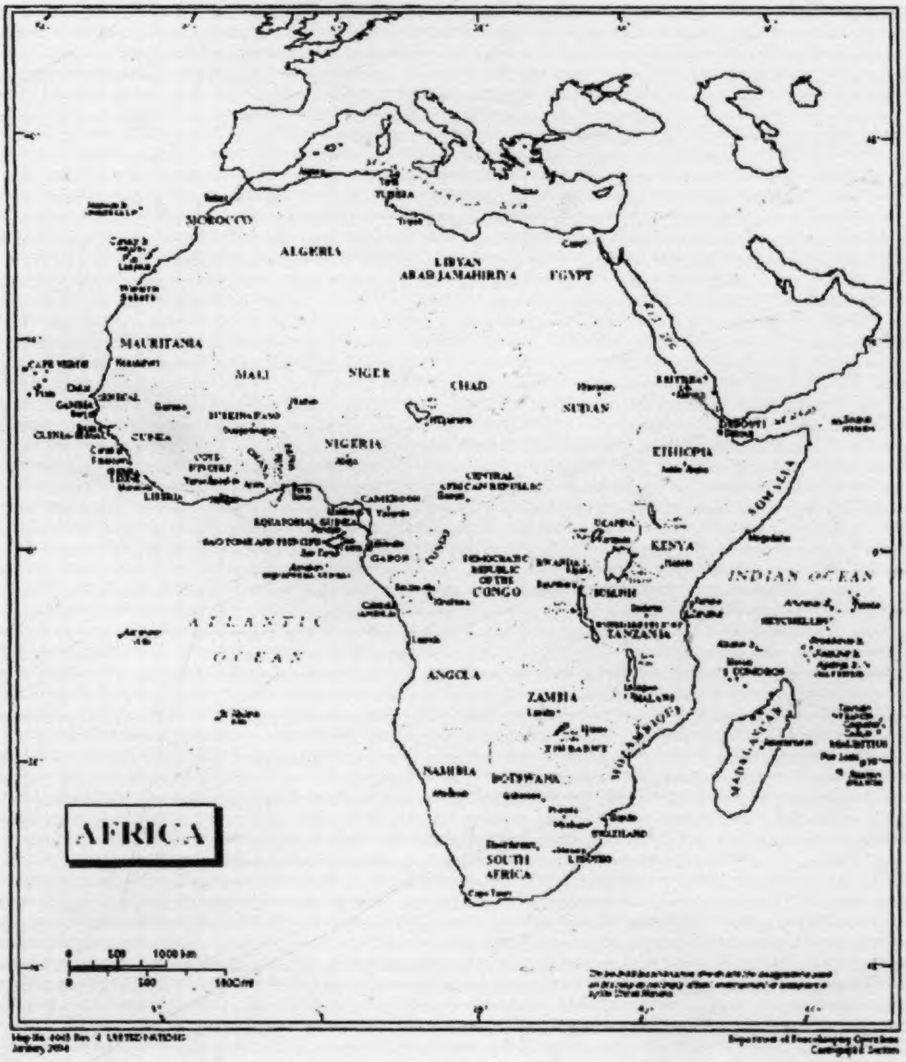
Weiss L., French PT., Waters M., Kluger M. and Agins B. (2000). Knowledge, attitudes and adherence to HAART: preliminary data from a multi-site adherence evaluation project. Int Conf AIDS. 2000 Jul 9-4; 13: abstract no. ThPeB5018.

Wenger N et al. (1999). Patient characteristics and attitudes associated with HAART adherence. 6th Conference on Retroviruses and Opportunistic Infections, Chicago, USA. Abstract no. 981.

WHO/UNAIDS AIDS 2006 Report on the global AIDS epidemic. The challenges of Antiretroviral Treatment (2006). Retrieved May 3, 2007 from http://www.who.int/medicines/publications/challenges_arvtreatment15Aug2006.pdf

WHO, "3 by 5" Uganda profile on treatment scale up, June 2005. Retrieved on March 28, 2006 from http://www.who.int/3by5/support/june2005_uga.pdf

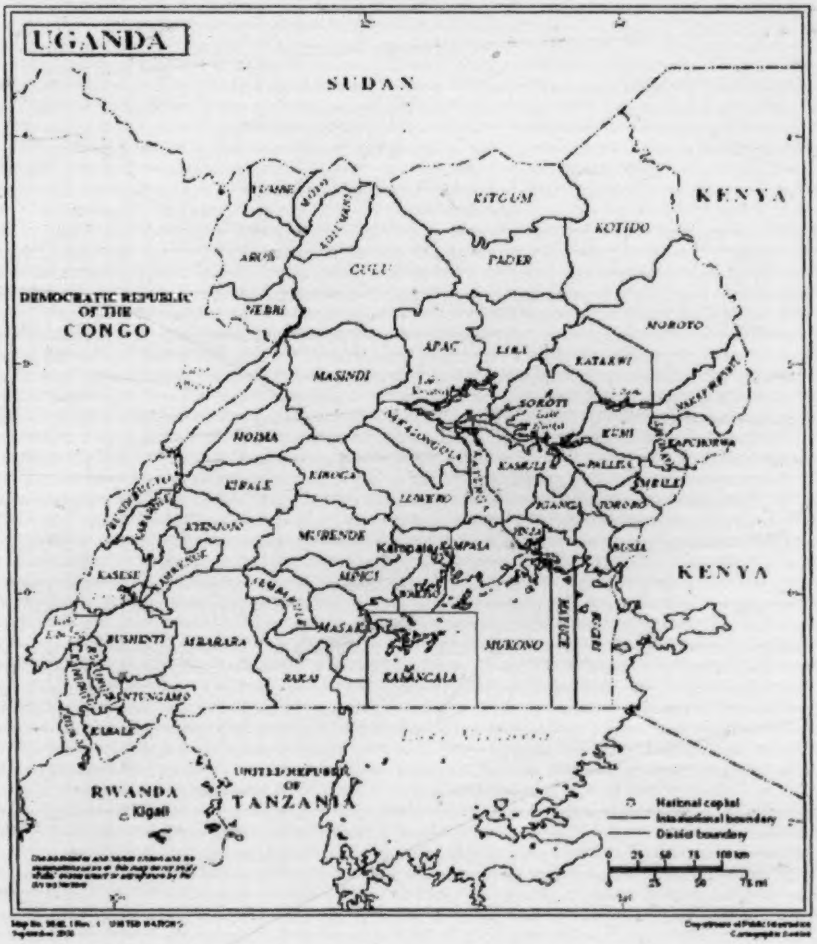
Appendix I: Map of Africa


AFRICA
MOROCCO
ALGERIA
LIBYAN ARAB JAMAHIRIYA
EGYPT
TUNISIA
MAURITANIA
CAPE VERDE
SENEGAL
GAMBIA
GUINEA
MALI
NIGER
CHAD
SUDAN
BURKINA FASO
NIGERIA
COTE D'IVOIRE
LIBERIA
CAMEROON
CENTRAL AFRICAN REPUBLIC
ETHIOPIA
ERITREA
DJIBOUTI
SOMALIA
EQUATORIAL GUINEA
SAO TOME AND PRINCIPE
GABON
CONGO
DEMOCRATIC REPUBLIC OF THE CONGO
UGANDA
KENYA
RWANDA
BURUNDI
UNITED REPUBLIC OF TANZANIA
INDIAN OCEAN
SEYCHELLES
COMOROS
ATLANTIC OCEAN
ANGOLA
ZAMBIA
MALAWI
MOZAMBIQUE
ZIMBABWE
MADAGASCAR
MAURITIUS
NAMIBIA
BOTSWANA
SWAZILAND
LESOTHO
SOUTH AFRICA
Cape Town
0 500 1000 km
0 500 1000 mi

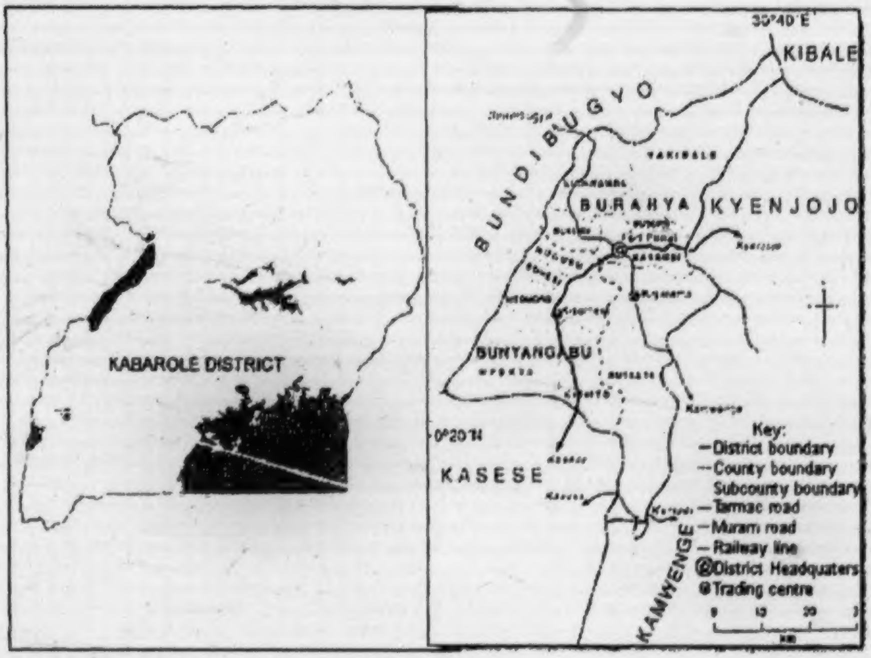
Map No. 4045 Rev. 4 UNITED NATIONS
January 2004

Department of Peacekeeping Operations
Cartographic Section

Appendix II: Map of Uganda


UGANDA
SUDAN
KENYA
KOTIDO
KITGUM
PADER
GULU
ARUA
NEBBI
DEMOCRATIC REPUBLIC OF THE CONGO
MOROTO
APAC
LIRA
KATAKWI
MASINDI
SOROTI
KUMI
HOIMA
KAPCHORWA
KAMULI
PALLISA
KIBALE
KIBOGA
LUWERO
MBALE
IGANGA
TORORO
KYENJOJO
MUBENDE
Kampala
KAMPALA
JINJA
BUSIA
KENYA
KASESE
MPIGI
MASAKA
BUSHENYI
MBARARA
MUKONO
RAKAI
KALANGALA
NTUNGAMO
KABALE
Lake Victoria
UNITED REPUBLIC OF TANZANIA
RWANDA
Kigali
National capital
International boundary
District boundary
0 25 50 75 100 km
0 25 50 75 mi

Appendix III: Map of Kabarole District


KABAROLE DISTRICT
30°40'E
KIBALE
BUNDIBUGYO
BURAHYA
KYENJOJO
Fort Portal
BUNYANGABU
0°20'N
KASESE
KAMWENGE
Key:
—District boundary
--County boundary
Subcounty boundary
—Tarmac road
—Muram road
—Railway line
Ⓡ District Headquaters
● Trading centre
0
10
20
km

Source: Kabarole District Information Portal, 2006.

APPENDIX IV : Consent Forms for Study Participants

UNIVERSITY OF ALBERTA

Title of Project

Barriers to the Acceptance of Free Postpartum Highly Active Antiretroviral Therapy (HAART) by HIV Positive mothers in Kabarole District, Uganda:

A Qualitative Study

Part 1: Research Information

Name of the Principle Investigator: Putu Duff

Affiliation: University of Alberta

Contact Information: (provide Ugandan cell phone number here upon arrival)

Name of Co-Investigator/Supervisor: Walter Kipp

Affiliation: University of Alberta

Contact Information: 1 (780) 492-8643

Part 2: Consent of Subject

	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, please provide your doctor's name:		

______________________________ **(This question is optional).**		

Part 3: Signatures

This study was explained to me by: ______________________________

Date: ______________________________

I agree to take part in this study:

Signature of Research Participant: ______________________________

Printed Name: ______________________________

Witness

Signature of witness: ______________________________

Name of witness: ______________________________

APPENDIX V: Letter of Introduction for Purpose of Research

IN ANY CORRESPONDENT ON THIS SUBJECT PLEASE QUOTE No:

Tel: 00256 483 22575

Fax: 00256 483 22743

13th September,
2006

……………………………………

……………………………………………………………

……………………………………………………………

RE: LETTER OF INTRODUCTION FOR PURPOSE OF RESEARCH:

Warm greetings from the District Directorate of Health Services of our District.

We have in our midst with us, students from University of Alberta, Canada.

The purpose of this letter is to introduce MS. PUTU DUFF, who will be carrying out a research entitled: "***Barriers to the Acceptance of Free postpartum Highly Active Antiretroviral Therapy (HAART) by HIV Positive mothers in Kabarole District, Uganda***"

Please accord her the usual welcome and assistance.

Thank you

Joa Okech Ojony Dr.

DISTRICT HEALTH OFFICER/KABAROLE

APPENDIX VI: Flyer for FGDs Participants

UNIVERSITY OF ALBERTA

Putu Duff, Principle Investigator

Masters of Science Student, Global Health

Department of Public Health Sciences

University of Alberta, Edmonton, AB

Phone: 233-9906

Tom Rubaale, Supervisor

Community Based ARV Project Centre

Fort Portal

Phone: 078856865

Title: Barriers to the Acceptance of Free Postpartum Highly Active Antiretroviral Therapy (HAART) by HIV Positive mothers in Kabarole District, Uganda: A Qualitative Study.

Study Purpose: We would like to invite you to participate in a study that we are doing about the acceptance of the free Highly Active Antiretroviral Therapy (HAART) that is offered to mothers through the antenatal clinics in Kabarole district. The information from this study will be used to find ways to improve the PMTCT Plus programme and increase the number of mothers who accept HAART.

What is Involved: The study involves an audio-taped group interview for one hour. This study will be completely confidential and will be carried out in a private room in the hospital at a time convenient to you. If you choose to participate, you will be completely reimbursed for any expenses related to participation in this study.

How to Participate: If you would like to participate in this study or have any questions, please call Putu Duff at 774301755 or Mr. Tom Rubaale at the Community Based ARV Project Centre in Fort Portal at 078856865.

APPENDIX VII: FLYER FOR INTERVIEW PARTICIPANTS

UNIVERSITY OF ALBERTA

Putu Duff, Principle Investigator

Masters of Science Student, Global Health

Department of Public Health Sciences

University of Alberta, Edmonton, AB

Phone: 774301755

Mr. Tom Rubaale

Community Based ARV Project Centre

Fort Portal

Phone: 078856865

Title: Barriers to the Acceptance of Free Postpartum Highly Active Antiretroviral Therapy (HAART) by HIV Positive mothers in Kabarole District, Uganda: A Qualitative Study.

Study Purpose: We would like to invite you to participate in a study that we are doing about the acceptance of the free Highly Active Antiretroviral Therapy (HAART) that is offered to mothers through the antenatal clinics in Kabarole district. We want to find out what are some of the difficulties for mothers to tak HAART and what are their views of HAART and Prevention of Mother to Child Transmission (PMTCT) programmes. The information from this study will be used to find ways to improve the PMTCT Plus programme and increase the number of mothers who accept HAART.

What is Involved: The study involves a one-on-one audio taped interview, approximately one hour in duration. This study will be completely confidential and will be carried out in a private room in the hospital at a time convenient to you. If you choose to participate, you will be completely reimbursed for any expenses related to participation in this study.

How to Participate: If you would like to participate in this study or have any questions, please call Putu Duff at 774301755 or Mr. Tom Rubaale at the Community Based ARV Project Centre in Fort Portal at 078856865.

APPENDIX VIII: Information Letter for Female Interview and FGD Participants

UNIVERSITY OF ALBERTA

Putu Duff, Principle Investigator

Master of Science Student, Global Health

Department of Public Health Sciences

University of Alberta, Edmonton, AB

Phone: 0774301755

Dr. Walter Kipp, Supervisor

Professor

Department of Public Health Sciences

University of Alberta Edmonton

Re: Barriers to the Acceptance of Free Postpartum Highly Active Antiretroviral Therapy (HAART) by HIV Positive mothers in Kabarole District, Uganda: A Qualitative Study

Study Purpose: We are doing a study because we want to know the reasons why some mothers do not accept free life-saving Highly Active Antiretroviral Therapy (HAART) that is offered to them. We want to find out what are some of the difficulties for mothers to take HAART and what are their views of HAART and Prevention of Mother to Child Transmission Plus (PMTCT-Plus) programmes. With this information, we hope to find ways to improve the PMTCT Plus programme and increase the number of mothers who accept HAART.

What is Involved: If you agree to participate in this study, you will be asked some questions. The questions will ask you about your age, your partner, the number of children that you have and if your partner or children have HIV. You will also be asked some questions about what you know about HAART and experiences with the PMTCT programme, counseling and staff. Questions about who you have told your HIV status, your health, about communication with your partner and any social support you may have. This should take no longer than one hour.

Risks and Benefits: You may feel shy or uncomfortable about answering some of these questions. Apart from this we do not know of any other risks from being part of the study.

Confidentiality: We will not use your names in this study. Only the researcher and the translator will be able to see the information that we collect today. WE will lock all information into a drawer for five years, and then destroy it. The consent forms and any field notes will also be locked in a drawer for five years and then be destroyed. We may publish or present the findings of this study, but we will note use your names.

Freedom to Withdraw: If you do not want to be in this study, you do not have to be in it. If you would like to stop being part of the study at any time, you can tell the researcher and we will stop the interview. If there are any questions you do not want to answer you do not need to answer them.

Questions and Concerns: If you have any questions about this study, you can call the principle investigator at 0774301755, or Mr. Tom Rubaale at the Health Department in Fort Portal at 048323043.

I agree to participate in this study:

Initial of Researcher.................................. Date.....................

Initial of Informant..................................... Date.....................

APPENDIX IX: Information Letter for Male FGD Participants

UNIVERSITY OF ALBERTA

Putu Duff, Principle Investigator

Master of Science Student, Global Health

Department of Public Health Sciences

University of Alberta, Edmonton, AB

Phone: 0774301755

Dr. Walter Kipp, Supervisor

Professor

Department of Public Health Sciences

University of Alberta Edmonton

Re: Barriers to the Acceptance of Free Postpartum Highly Active Antiretroviral Therapy (HAART) by HIV Positive mothers in Kabarole District, Uganda: A Qualitative Study

Study Purpose: We are doing a study because we want to know what men think about why mothers do not accept free life-saving Highly Active Antiretroviral Therapy (HAART) that is offered to them. We want to find out what men's views on HAART are and what they think are the difficulties for mothers to take HAART. We would also like to find what role men think they play in his partner's decision to start HAART. With this information, we hope to find ways to improve the PMTCT Plus programme and increase the number of mothers who accept HAART.

What is Involved: If you agree to participate in this study, you will be asked some questions. We will first explain the situation of low acceptance of HAART treatment by mothers. The questions will be about this topic. WE will ask questions about what you know about HAART, why you think mothers would not take free HAART, the role of a man in his partner's decision to take HAART and communication about HIV and HAART between the mother an her partner. This should take no longer than one hour.

Risks and Benefits: You may feel shy or uncomfortable about answering some of these questions. Apart from this we do not know of any other risks from being part of the study.

Confidentiality: We will not use your names in this study. Only the researcher and the translator will be able to see the information that we collect today. WE will lock all information into a drawer for five years, and then destroy it. The consent forms and any field notes will also be locked in a drawer for five years and then be destroyed. We may publish or present the findings of this study, but we will note use your names.

Freedom to Withdraw: If you do not want to be in this study, you do not have to be in it. If you would like to stop being part of the study at any time, you can tell the researcher and we will stop the interview. If there are any questions you do not want to answer, you do not need to answer them.

Questions and Concerns: If you have any questions about this study, you can call the principle investigator at 0774301755, or Mr. Tom Rubaale at the Health Department in Fort Portal at 048323043.

I agree to participate in this study:

Initial of Researcher.................................. Date.....................

Initial of Informant.................................. Date.....................

APPENDIX X: Topic List for Group 1: Never Enrolled for Treatment

UNIVERSITY OF ALBERTA

1. Demographics:

a) How old are you?

b) What is your marital status?

c) Has your partner been tested for HIV?

d) Do you have children?
  - How many children do you have?
  - What are the ages of your children?
  - Have these children been tested?
  - Have any been found to be HIV+? If so, are they taking HAART?

e) How do you earn a living?

f) Is your partner employed/ How does your partner earn a living?

g) What is your estimated income?

h) Have you gone to school?
  - What is the level/type/grade of education you have completed?

i) Has your partner gone to school?
  - What is the level/type/grade of education has he completed?

j) Are you religious? If so, which faith do you practice?

2. Views about PMTCT-Plus and ARV Programme

Conveniences of Services

a) Where do you live? How far is the clinic from your home?
  - What means do you use to come to the clinic from your home?
  - How does the distance to the clinic affect your decision to take HAART?

b) How much does it cost to make visits to the clinic? (In terms of travel costs, missing time from work, cost of leaving children?

- How do these costs affect your decision to take HAART?

c) Is the clinic open at times that are convenient to you?

- Explain.

d) How long do you find your visits to the clinic to be?

- How long are the waiting times?
- How does this length of time at the clinic affect your decision to return for HAART?

Counseling sessions

e) Were you counseled about HAART?

Experiences with the Programme Staff

f) How would you describe your experiences with the programme staff?

g) How knowledgeable/helpful/courteous do you find the programme staff?

h) Do you trust the programme staff to keep your HIV status confidential?

- What makes you think this?

3. HAART Knowledge

a) What were you told about HAART in your counseling sessions?

b) What did you know about HAART before your counseling sessions?

- Where did you learn this?

c) Do you believe that HAART is effective in treating HIV positive patients?

- Why/Why not?

d) Describe the benefits of HAART that you know

e) Describe the side effects of taking HAART that you know

- How does knowledge of these side effects influence your decision to take HAART?

f) Describe the treatment routine of someone on HAART.

g) Do you know anyone who is/or was taking HAART?

- What have they told you about their experiences taking HAART?
- How does this affect your decision to start treatment?

h) Do you think your HAART knowledge level is enough to start HAART?

- Why/why not?
- If you knew more would you be more likely to start HAART?
- Why or Why not?

4. Impact of HAART on patient

a) How do you think taking HAART would change your life?

b) Are you prepared to take HAART in the future?

- What makes you think this?

c) Are you taking any other treatments for HIV? Traditional medicines?

- What are these?
- Who suggested you take this treatment?

5. Serostatus Disclosure

a) Have you shared your HIV positive status with your partner?

b) Have you told anyone else that you are HIV positive?

6. Support

a) Have you talked to anyone about taking HAART? Who?

- Do they encourage/discourage you to take HAART? How?

b) What is your partner's/family's/friend's view on HAART?

- How does their view of HAART affect your decision to start treatment?

c) Do you have anyone to support you if you were to take HAART?

- If YES: Who? How would they support you?
- If NO: Would you take HAART if you had more social support?
- How does social support affect your decision to take HAART?

7. Confidentiality

a) Do you think your partner will discover your HIV status if you begin taking HAART? Why? Why not?

b) Do you think your family/friends/community will discover you HIV status if you begin taking HAART?

- If Yes: How? How does this affect your decision to take HAART?
- If No: Why not?

8. HIV/AIDS Stigma

a) How do you think your community views AIDS patients?

b) How do you think your community views HAART patients?

c) Do you feel HIV/AIDS stigmas exists within your community?

- How does this affect your decision to take HAART?
- How do you think HIV/AIDS stigma affect other HAART patients?

9. Patient Factors and Health Care Autonomy

a) How would you describe your current health?

- How does your health state affect your decision to take HAART?

b) Describe the activities/duties that occupy your time.

- How does this affect your ability to come to the clinic for HAART?

c) Are you able to visit the clinic without consulting your partner?

- Explain.

d) What are your reasons for not starting HAART?

e) What do you think are the reasons other PMTCT-Plus patients do not start HAART?

f) Are there any other comments you would like to add about the barriers to taking HAART?

g) Do you have any questions?

APPENDIX XI: Topic List for Group 2- Enrolled but Never returned for HAART

UNIVERSITY OF ALBERTA

1.Demographics:

a) How old are you?

b) What is your marital status?

- Are you living with your partner?

c) Has your partner been tested for HIV?

d) Do you have children?

- How many children do you have?
- What are the ages of your children?
- Have these children been tested?
- Have any been found to be HIV+? If so, are they taking HAART?

e) How do you earn a living?

f) Is your partner employed/ How does your partner earn a living?

g) What is your estimated income?

h) Have you gone to school?

- What is the level/type/grade of education you have completed?

i) Has your partner gone to school?

- What is the level/type/grade of education has he completed?

j) Are you religious? If so, which faith do you practice?

2. Views about PMTCT-Plus and ARV Programme

Conveniences of Services

a) Where do you live? How far is the clinic from your home?

- What means do you use to come to the clinic from your home?
- How does the distance to the clinic affect your decision to take HAART?

b) How much does it cost to make visits to the clinic? (In terms of travel costs, missing time from work, cost of leaving children?

- How do these costs affect your decision to take HAART?

c) Is the clinic open at times that are convenient to you?

- Explain.

d) How long do you find your visits to the clinic to be?

- How long are the waiting times?
- How does this length of time at the clinic affect your decision to return for HAART?

Counseling sessions

a) Were you counseled about HAART?

b) How long was your counseling session?

- Was this time enough?

c) What were you told in the counseling session?

- Did you understand all that you were taught?
- Was this enough information to make a decision about starting HAART?

d) Did the counselor make you feel comfortable?

- Why/Why not?
- Were you able to ask questions?

e) How did the counseling session influence your decision to not start treatment?

f) How helpful/effective do you think the counseling sessions are?

- How can counseling be improved?

Experiences with the Programme Staff

a) How would you describe your experiences with the programme staff?

- Have you had any negative experiences?

- Explain.
- How do your experiences with the programme staff affect your decision to return to the clinic?

b) How knowledgeable/helpful/courteous do you find the programme staff?

c) Do you trust the programme staff to keep your HIV status confidential?

- What makes you think this?

3. HAART Knowledge

i) What were you told about HAART in the Enrolment counseling sessions?

j) What did you know about HAART before your counseling sessions?

- Where did you learn this?

k) Do you believe that HAART is effective in treating HIV positive patients?

- Why/Why not?

l) Describe the benefits of HAART that you know

m) Describe the side effects of taking HAART that you know

- How does knowledge of these side effects influence your decision to take HAART?

n) Describe the treatment routine of someone on HAART.

- How many times a day is HAART taken?
- What duration is HAART taken for?
- How do these influence your decision to take HAART?

o) Do you know anyone who is/or was taking HAART?

- What have they told you about their experiences taking HAART?
- How does this affect your decision to start treatment?

p) Do you think your HAART knowledge level is enough to start HAART?

- Why/why not?
- If you knew more would you be more likely to start HAART?
- Why or Why not?

4. Impact of HAART on patient

a) How do you think taking HAART would change your life?

b) Are you prepared to take HAART in the future?

- ➢ What makes you think this?

d) Are you taking any other treatments for HIV? Traditional medicines?

- ➢ What are these?
- ➢ Who suggested you take this treatment?

5. Serostatus Disclosure

c) Have you shared you HIV positive status with your partner?

- ➢ If Yes: What was his response to your disclosure?
- ➢ How does this affect your decision to take treatment?

d) Have you told anyone else that you are HIV positive?

- ➢ If Yes: Who is this?/ What was their response? How does this affect your decision to take HAART?
- ➢ If no: Why have you not told anyone else?

6. Support

a) Have you talked to anyone about taking HAART? Who?

- ➢ Do they encourage/discourage you to take HAART? How?

b) What is your partner's/family's/friend's view on HAART?

- ➢ How does their view of HAART affect your decision to start treatment?

c) Do you have anyone to support you if you were to take HAART?

- ➢ If YES: Who? How would they support you?
- ➢ If NO: Would you take HAART if you had more social support?
- ➢ How does social support affect your decision to take HAART?

7. Confidentiality

a) Do you think your partner will discover your HIV status if you begin taking HAART?

- If Yes: How? How does this affect your decision to take HAART?
- If No: Why not?

b) Do you think your family/friends/community will discover you HIV status if you begin taking HAART?

- If Yes: How? How does this affect your decision to take HAART?
- If No: Why not?

8. HIV/AIDS Stigma

c) How do you think your community views AIDS patients?

- How does this affect your decision to take HAART?

d) How do you think your community views HAART patients?

- How does this affect your decision to take HAART?

c) Do you feel HIV/AIDS stigmas exists within your community?

- How does this affect your decision to take HAART?
- How do you think HIV/AIDS stigma affect other HAART patients?

9. Patient Factors and Health Care Autonomy

a) How would you describe your current health?

- How does your health state affect your decision to take HAART?

g) Describe the activities/duties that occupy your time.

- How does this affect your ability to come to the clinic for HAART?

h) Are you able to visit the clinic without consulting your partner?

- Explain.

i) What are your reasons for not starting HAART?

j) What do you think are the reasons other PMTCT-Plus patients do not start HAART?

k) Are there any other comments you would like to add about the barriers to taking HAART?

g) Do you have any questions?

APPENDIX XII: Topic List for Group 3- Defaulted HAART

UNIVERSITY OF ALBERTA

1.Demographics:

k) How old are you?

l) What is your marital status?

  - Are you living with your partner?

m) Has your partner been tested for HIV?

n) Do you have children?

  - How many children do you have?
  - What are the ages of your children?
  - Have these children been tested?
  - Have any been found to be HIV+? If so, are they taking HAART?

o) How do you earn a living?

p) Is your partner employed/ How does your partner earn a living?

q) What is your estimated income?

r) Have you gone to school?

  - What is the level/type/grade of education you have completed?

s) Has your partner gone to school?

  - What is the level/type/grade of education has he completed?

t) Are you religious? If so, which faith do you practice?

2. Views about PMTCT-Plus and ARV Programme

☆ Ask this set of questions twice, once for GTZ run and again for Yellow House

Conveniences of Services

e) Where do you live? How far is the clinic from your home?

- ➢ What means do you use to come to the clinic from your home?
- ➢ How did the distance to the clinic affect your decision to default HAART?

f) How much does it cost to make visits to the clinic? (In terms of travel costs, missing time from work, cost of leaving children?

- ➢ How do these costs affect your decision to take HAART?

g) Is the clinic open at times that are convenient to you?

- ➢ Explain.

h) How long do you find your visits to the clinic to be?

- ➢ How long are the waiting times?
- ➢ How does this length of time at the clinic affect your decision to default HAART?

Counseling sessions

g) Were you counseled about HAART?

h) How long was your counseling session?

- ➢ Was this time enough?

i) What were you told in the counseling session?

- ➢ Did you understand all that you were taught?
- ➢ Was this enough information to make a decision about continuing HAART?

j) Did the counselor make you feel comfortable?

- ➢ Why/Why not?
- ➢ Were you able to ask questions?

k) How did the counseling session influence your decision to stop treatment?

l) How helpful/effective do you think the counseling sessions are?

- ➢ How can counseling be improved?

Experiences with the Programme Staff

d) How would you describe your experiences with the programme staff?

- Have you had any negative experiences?
- Explain.
- How did your experiences with the programme staff affect your decision to stop HAART?

e) How knowledgeable/helpful/courteous do you find the programme staff?

f) Do you trust the programme staff to keep your HIV status confidential?

- What makes you think this?

3. HAART Knowledge

q) What were you told about HAART in the Enrolment counseling sessions?

r) What did you know about HAART before your counseling sessions?

- Where did you learn this?

s) Do you believe that HAART is effective in treating HIV positive patients?

- Why/Why not?

t) Describe the benefits of HAART that you know

u) Describe the side effects of taking HAART that you know

- How does knowledge of these side effects influence your decision to stop HAART?

v) Describe the treatment routine of someone on HAART.

- How many times a day is HAART taken?
- What duration is HAART taken for?
- How do these influence your decision to stop HAART?

w) Do you know anyone who else is/or was taking HAART?

- What have they told you about their experiences taking HAART?
- How does this affect your decision to default treatment?

x) Do you think your HAART knowledge level is enough to start HAART?

- Why/why not?
- If you knew more would you be more likely to continue HAART?
- Why or Why not?

4. **Impact of HAART on patient**

a) How do you think taking HAART would change your life?

b) Are you prepared to take HAART in the future?

- What makes you think this?

e) Are you taking any other treatments for HIV? Traditional medicines?

- What are these?
- Who suggested you take this treatment?

5. **Serostatus Disclosure**

e) Have you shared you HIV positive status with your partner?

- If Yes: What was his response to your disclosure?
- How does this affect your decision to default treatment?

f) Have you told anyone else that you are HIV positive?

- If Yes: Who is this?/ What was their response? How does this affect your decision to default HAART?
- If no: Why have you not told anyone else?

6. **Support**

a) Have you talked to anyone about taking HAART? Who?

- Do they encourage/discourage you to take HAART? How?

b) What is your partner's/family's/friend's view on HAART?

- How does their view of HAART affect your decision to default treatment?

c) Do you have anyone to support you if you were to take HAART?

- If YES: Who? How would they support you?
- If NO: Would you take HAART if you had more social support?
- How does social support affect your default HAART?

7. Experiences Taking HAART

a) How long has it been since you stopped taking HAART?

b) How long had you been taking HAART before stopping?

c) Do you feel that your health improved while you were on HAART? Explain.

d) Did you experience any side effects while you were taking HAART?

- Explain what these are.
- Did you consult with a Health Care Worker about these side effects? What did they advise you?
- How did side effects influence you decision to stop HAART?

e) How well were you able to adhere to HAART while you were taking the drugs?

f) Were you able to eat the nutritious foods require while you were taking HAART?

- How did affect you decision to take/default HAART?

g) Were you able to practice unprotected sex while on HAART?

- How did this affect your decision to default HAART?

8. Decision to Default HAART

a) Did you consult with anyone before stopping HAART?

- If YES: Who? What did they tell you? Did this influence you decision to stop HAART?
- If NO: Why not?

b) What made you decide to stop your HAART?

9. Confidentiality

a) Do you think your partner will discover your HIV status if you continue to take HAART?

- How would he find out?
- How did this affect your decision to default HAART?

b) Do you think your family/friends/community will discover you HIV status if you continue taking HAART?

- How would they find out?
- How did this affect your decision to default HAART?

10. HIV/AIDS Stigma

e) How do you think your community views AIDS patients?

- How does this affect your decision to default HAART?

f) How do you think your community views HAART patients?

- How does this affect your decision to take HAART?

c) Do you feel HIV/AIDS stigmas exists within your community?

- How does this affect your decision to stop HAART
- How do you think HIV/AIDS stigma affect other HAART patients?

11. Patient Factors and Health Care Autonomy

a) How would you describe your current health?

- How does your health state affect your decision to default or continue treatment?

l) Describe the activities/duties that occupy your time.

- How does this affect your ability to come to the clinic for HAART?

m) Are you able to visit the clinic without consulting your partner?

- Explain. Did this affect your decision to stop HAART?

n) What are your reasons for stopping HAART?

o) What do you think are the reasons other PMTCT-Plus patients do not take HAART?

p) Are there any other comments you would like to add about the barriers to taking HAART?

g) Do you have any questions?

APPENDIX XIII: Topic List for Group 4- Patients Taking HAART

UNIVERSITY OF ALBERTA

1.Demographics:

a) How old are you?

b) What is your marital status?

  - Are you living with your partner?

c) Has your partner been tested for HIV?

d) Do you have children?

  - How many children do you have?
  - What are the ages of your children?
  - Have these children been tested?
  - Have any been found to be HIV+? If so, are they taking HAART?

e) How do you earn a living?

f) Is your partner employed/ How does your partner earn a living?

g) What is your estimated income?

h) Have you gone to school?

  - What is the level/type/grade of education you have completed?

i) Has your partner gone to school?

  - What is the level/type/grade of education has he completed?

j) Are you religious? If so, which faith do you practice?

2. *Views about PMTCT-Plus and ARV Programme*

☆ Ask this set of questions twice, once for GTZ run and again for Yellow House

Conveniences of Services

a) Where do you live? How far is the clinic from your home?

- What means do you use to come to the clinic from your home?
- How did the distance to the clinic affect your decision to take HAART?

b) How much does it cost to make visits to the clinic? (In terms of travel costs, missing time from work, cost of leaving children?

- How do these costs affect your decision to take HAART?

c) Is the clinic open at times that are convenient to you?

- Explain.

d) How long do you find your visits to the clinic to be?

- How long are the waiting times?
- How does this length of time at the clinic affect your decision to takeHAART?

Counseling sessions

e) Were you counseled about HAART?

f) How long was your counseling session?

- Was this time enough?

g) What were you told in the counseling session?

- Did you understand all that you were taught?
- Was this enough information to make a decision about continuing HAART?

h) Did the counselor make you feel comfortable?

- Why/Why not?
- Were you able to ask questions?

i) How did the counseling session influence your decision to take treatment?

j) How helpful/effective do you think the counseling sessions are?

- How can counseling be improved?

Experiences with the Programme Staff

k) How would you describe your experiences with the programme staff?

- Have you had any negative experiences?

- Explain.
- How did your experiences with the programme staff affect your decision to take HAART?

l) How knowledgeable/helpful/courteous do you find the programme staff?

m) Do you trust the programme staff to keep your HIV status confidential?

- What makes you think this?

3. HAART Knowledge

a) What were you told about HAART in the Enrolment counseling sessions?

b) What did you know about HAART before your counseling sessions?

- Where did you learn this?

c) Do you believe that HAART is effective in treating HIV positive patients?

- Why/Why not?

d) Describe the benefits of HAART that you know

e) Do you know anyone who else is/or was taking HAART?

- What have they told you about their experiences taking HAART?
- How does this affect your decision to default treatment?

f) Do you think your HAART knowledge level is enough to continue HAART?

- Why/why not?
- If you knew more would you be more likely to continue HAART?
- Why or Why not?

4. Serostatus Disclosure

a) Have you shared you HIV positive status with your partner?

- If Yes: What was his response to your disclosure?
- How does this affect your decision to take HAART?
- If No: Why have you not told your partner?

b) Have you told anyone else that you are HIV positive?

- If Yes: Who is this?/ What was their response? How does this affect your decision to take HAART?
- If no: Why have you not told anyone else?

5. Support

a) Have you talked to anyone about taking HAART before you started? Who?

- Do they encourage/discourage you to take HAART? How?

b) What is your partner's/family's/friend's view on HAART?

- How does their view of HAART affect your decision to take treatment?

c) Do you have anyone to support you if you were to take HAART?

- If YES: Who? How would they support you?
- If NO: How would having social support affect your decision to take HAART?

6. Experiences Taking HAART

a) How long have you been taking HAART?

b) Do you feel that your health improved while you were on HAART? Explain.

c) Have you stopped taking HAART at any point since you began treatment?

d) Did you experience any side effects while you were taking HAART?

- Explain what these are.
- Did you consult with a Health Care Worker about these side effects? What did they advise you?
- How did side effects influence you decision to stop HAART?

e) Are you able to eat the nutritious foods require while you were taking HAART?

- How did affect you decision to take HAART?

c)Are you able to practice unprotected sex while on HAART?

- How does this affect your decision to default HAART?

7. Confidentiality

a) Do you think your partner will discover your HIV status if you continue to take HAART?

- How would he find out?
- How did this affect your decision to take HAART?

b) Do you think your family/friends/community will discover you HIV status if you continue taking HAART?

- How would they find out?
- How did this affect your decision to continue to take HAART?

8. HIV/AIDS Stigma

a) How do you think your community views AIDS patients?

- How does this affect your decision to takeHAART?

b) How do you think your community views HAART patients?

- How does this affect your decision to take HAART?

c) Do you feel HIV/AIDS stigmas exists within your community?

- How does this affect your decision to continue HAART?
- How do you think HIV/AIDS stigma affect other HAART patients?

8. Patient Factors and Health Care Autonomy

a) How would you describe your current health?

- How does your health state affect your decision to continue treatment?

b) Describe the activities/duties that occupy your time.

- How does this affect your ability to come to the clinic for HAART?/ Do they interfere with your ability to take HAART?

c) Are you able to visit the clinic without consulting your partner?

- Explain. Did this affect your decision to stop HAART?

d) What are your reasons for stopping HAART?

e) What do you think are the reasons other PMTCT-Plus patients do not take HAART?

f) Are there any other comments you would like to add about the barriers to taking HAART?

g) Do you have any questions?

APPENDIX XIV: Focus Group Discussion Guide: Male Participants

UNIVERSITY OF ALBERTA

(RA Explains the occurrence of low access and acceptance of free HAART by PMTCT-Plus clients. RA ensures that the points below are communicated)

- Pregnant women are tested for HIV through the clinic when they become pregnant and give birth.
- Those women that are found positive are offered free treatment for their HIV called HAART
- Some of these women don't accept this free treatment, while others start and then stop.
- We are trying to find out reasons why women don't accept HAART. We would like to ask you some questions about HAART and why you think some women don't accept this treatment?
- Are there any questions before we start the session?
- (Make sure everyone fully understands the scenario before beginning)

Views on HAART

1. What do you know about HAART?
    - Describe the benefits and side effects associated with HAART that you know.
    - Where did you learn about HAART?
2. How often does an AIDS patient on HAART take their pills each day?

    How long is HAART taken for?
3. Do you think HAART is effective in treating HIV/AIDS?
    - Why or why not?

Views on HIV Testing

4. There are very few men that test for HIV compared to the women.
    - Why do you think few men test for HIV?

- How do you think a man's failure to test for HIV could affect his partner's decision to take HAART?
- What could be done to increase the number of men tested for HIV?

HIV Serostatus Disclosure

5. Do you think that women would tell their partners about their HIV status?
    - Why/Why not?
    - How do you think this affects a woman's decision to take HAART?
6. If you were HIV positive would you tell your wife your status?
    - Why/Why not?

Social Support

7. Would a man encourage or discourage his partner to take HAART?
    - Why/Why not?
8. How do you think partner support to take HAART affects his wife's decision to take HAART?

Health Care Autonomy

9. What do you think is a man's role in his partner's decision to take HAART?
10. What do you think are the reasons some women do not take the free HAART offered to them?
11. Do you have any further questions about this topic? Any comments you would like to add?

UNIVERSITY OF ALBERTA

Female Focus Group Discussion Guide

Views of Buhinga's PMTCT-Plus Programme

a) Physical features of the clinic

1) How far is the clinic from your home? How does this distance and cost affect your decision to return for HAART?

b) PMTCT-Plus Staff and Services

2) How long are the waiting times at the clinic before you see health care worker? How does this wait time affect your decision to return to the clinic for HAART?

3) How would you describe your overall experiences with the health care staff?

   - How does your experience with the programme staff affect your decision to return to the clinic for HAART?

Knowledge of HAART

4) What were you told about HAART by the counselor before starting HAART?
   - Do you think this is enough for you to make a decision to start HAART? Explain?
   - How do you think counseling could be improved?

5) Do you think that HAART is effective in treating HIV/AIDS? Why or why not?

HIV Serostatus Disclosure and Confidentiality

6) Have you told anyone about your HIV positive status?
    - Have you told your partner about HIV status? Why/Why not?

7) Do you think your family/community will know you are HIV positive if they saw you taking HAART? Why/Why not?
    - How does this affect your decision to start HAART?

Social Support

8) Do you have anyone to support you while you are taking HAART?
    - Who?
    - How do they support you?
    - How does this support/lack of support affect your decision to take HAART?
9) What are your reasons for not starting HAART?
    - What do you think are other women's reasons for not starting HAART?
10) Do you have any questions or comments you would like to make on this topic?